

**THE EXPERIENCE OF HIV STATUS DISCLOSURE TO ADOLESCENTS IN HHOHHO
REGION: SWAZILAND**

by

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DECLARATION

I declare that **THE EXPERIENCE OF HIV STATUS DISCLOSURE TO ADOLESCENTS IN HHOHHO REGION: SWAZILAND** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.



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THE EXPERIENCE OF HIV STATUS DISCLOSURE TO ADOLESCENTS IN HHOHHO REGION: SWAZILAND

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ABSTRACT

This study used a qualitative, explorative, and descriptive design to understand the experiences of adolescents after HIV status disclosure in Hhohho region Swaziland. The data were collected through in-depth individual semi structured face-to-face interviews from 10 adolescents living with HIV between the ages 15-19 years. To analyse interviews, Tesch's qualitative data analysis approach was used.

Findings from the study revealed that participants experienced sadness, despair and anger after disclosure and also had fear of death because some had lost one or both parents. The participants reported recurrent episodes of poor health, which resulted in failure at school. In addition, they stressed that they could not disclose their HIV status because they feared discrimination and stigma.

Recommendations were made to improve coping strategies of adolescents and revising the nursing curriculum to equip nursing students with appropriate skills that would enable them to care for adolescents living with HIV (ALHIV).

KEY CONCEPTS

Adolescent; AIDS; anti-retroviral therapy; disclosure; discrimination; caregivers; experience; health care practitioners; HIV; Swaziland.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ALHIV	Adolescents Living with HIV
ART	Anti-Retroviral Therapy
HIV	Human Immunodeficiency Virus
SSA	Sub-Saharan Africa
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's International Emergency Fund
WHO	World Health Organization

CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

The Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) pandemic is a global concern and it is considered as one of the most destructive pandemics in history (Andersson & Svensson 2016:5). As stated in the Stephen Lewis Foundation (2015a:1), approximately 37 million people are living with HIV worldwide. In addition, since the beginning of the HIV pandemic, an estimated 39 million people have died of HIV/AIDS-related conditions like tuberculosis, kaposi sarcoma and cryptococcal meningitis according to the Joint United Nations Programme on HIV and AIDS (UNAIDS 2011:22).

It is also stated in this foundation that sub-Saharan Africa (SSA) is home to roughly 70% of all people living with HIV, but only has 15% of the global population (Stephen Lewis Foundation 2015a:1). Between 2009 and 2013, the estimated number of adolescents living with HIV increased from 1.9 million to 2.1 million, with over 80% of them residing in southern and East Africa. HIV/AIDS has emerged as the second largest cause of death for adolescents globally, with a 50% increase in HIV/AIDS related deaths among adolescents between 2005 and 2013. Furthermore, less than one in five adolescent girls and an even lesser proportion of adolescent boys were aware of their HIV status in 2013 (Stephen Lewis Foundation 2015a:2).

Swaziland is one of the countries that is severely affected by HIV/AIDS. The first AIDS case in Swaziland was reported in 1987 (World Health Organization 2005:1) and today more than one in three adults is infected as Swaziland faces a generalised HIV/AIDS pandemic. Rural and urban areas do not differ significantly. Poverty, unemployment and a large migrant population have fuelled the pandemic (World Health Organization 2005:1).

Furthermore, conservative religious and traditional beliefs against condom use and frequent multiple partners have severely affected society and the economy (World

Health Organization 2005:1). Economic growth remained stagnant averaging 1.7% between 2012 and 2013, one of the lowest rates in Africa as reported by United Nations International Children's Emergency Fund (UNICEF 2013:1).

The adolescents in Swaziland are also affected by the pandemic, as an estimated 11 000 of those living with HIV were adolescents in 2013 (UNAIDS 2014:2). Advances in HIV testing and anti-retroviral therapy (ART) has led to an increased life expectancy of adolescents living with HIV, and this has posed a new challenge regarding HIV status disclosure in this group. UNICEF (2011:6) refers to adolescence as the period in human growth and development that occurs after childhood and before adulthood, from ages 10-19. In this study, an adolescent is a person between the ages of 15-19 who is living with HIV. This chapter outlines background information about the research problem, aim of the study, significance, study design, and scope of the study.

1.2 BACKGROUND INFORMATION ABOUT THE RESEARCH PROBLEM

HIV/AIDS in adolescents continue to be a global concern. The number of children living with HIV and AIDS is on the rise. They account for about 3.3 million (6%) of all HIV infections worldwide with the majority (91%) of the infections occurring in SSA (Phuma-Ngaiyaye & Dartey 2015:1).

Swaziland is one of the countries that are severely affected by the HIV pandemic as it is said to have the highest HIV prevalence in the world, with 26% of its population in the 15-49 age group living with HIV (UNICEF 2013:2). Women are disproportionately affected with the prevalence being 31% compared to 20% in men (UNICEF 2013:2). The total population in Swaziland is 1.1 million people. Out of this number, people living with HIV in Swaziland is 210,000 (Stephen Lewis Foundation 2015b:3).

According to Kidia, Mupambireyi, Cluver, Ndhlovu, Borok and Ferrand (2014:1), owing to the scale up of ART over the last decade, the survival of adolescents living with HIV (ALHIV) has improved dramatically, enabling them to live into adolescence and beyond. As they do, the issue of informing them about their HIV status arises (Kidia et al 2014:1). A minority of these adolescents are aware of their HIV status.

Swaziland introduced ART in 2003 and now a decade later, some of the clients who were enrolled during infancy have reached the stage of adolescence. The disclosure of a diagnosis of HIV to infected adolescents is not only difficult but stressful to both adolescents and caregivers. Caregivers are reluctant to disclose the HIV status to the adolescents living with HIV because of fear of unknown negative feelings the disclosure may evoke.

In addition, most caregivers have found disclosure of HIV status to adolescents very nerve-racking because of the fear that HIV disclosure would eventually expose the family's own diagnosis (Phuma-Ngaiyaye & Dartey 2015) citing (Delaney, Serovich & Lim 2009:175). The caregivers also fear that the adolescents may accidentally disclose the facts to others leading to social stigma and discrimination.

Knowing one's HIV status is recognised as an important prerequisite for effective adherence to ART (Kidia et al 2014:1). Furthermore, while there is little evidence that disclosure causes psychological harm, research suggests that it may actually be beneficial for a young person's mental well-being (Kidia et al 2014:2). Disclosure allows the young person to have access to social support and lessens depression in the long-term because of better understanding of the disease while allowing them to take control over their health (Vaz, Maman, Eng, Barbarin, Tshikandu & Behets 2012:3).

Another study conducted in Zambia by Mburu, Hodgson, Kalibala, Haamujompa, Cataldo, Lowenthal and Ross (2010:2) affirm that disclosing an HIV status to the adolescent living with HIV fulfils their right to know about their own health, improves adherence to ART and retention in care ultimately leading to prolonged survival. Psychologically, it can also boost their self-esteem, help them cope better with stigma and promote responsible sexual behaviours.

Mutumba, Musiime, Tsai, Byaruhanga, Kiweewa, Bauermeister and Snow (2015:473) also assert that adolescents who are aware of their HIV status are more engaged in health care decision-making, and have higher self-esteem, improved access to social support and better relationships with their caregivers. Conversely, non-disclosure and partial disclosure have been associated with inadequate knowledge about HIV, poor adherence to ART, poor psychosocial adjustment, and poor coping mechanisms.

A few studies in sub-Saharan Africa explored the experiences of adolescents living with HIV after status disclosure. In particular, the researcher found no similar study conducted in Swaziland. In a study conducted in Uganda by Mutumba et al (2015:478), the majority of respondents reported a varied array of unpleasant emotions after disclosure, although a significant number also reported neutral reactions. A minority of respondents reported positive emotions such as relief and happiness. Respondents' reactions to disclosure were closely associated with previous knowledge about HIV, health status at the time of disclosure, previous knowledge or experience with people living with HIV, and their gender and age at disclosure. None of the respondents reported receiving any counselling support following the disclosure event.

In another study conducted in Malawi by Phuma-Ngaiyaye and Dartey (2015:7) revealed that the disclosure of HIV diagnosis to infected children continues to be a dilemma, with most caregivers perceiving it as difficult and stressful. However, adolescents voiced out that they want to be told their HIV diagnosis before they are introduced to medication.

Owing to the unavailability of another documented study in Swaziland, the researcher felt that it would be beneficial to conduct this study in the country in order to bring forth how non-disclosure and late disclosure affect adolescents living with HIV. It is envisaged that the study will determine care and support services that are appropriate for this age group leading to less negative experiences.

1.3 STATEMENT OF THE RESEARCH PROBLEM

The disclosure of an HIV status to adolescents living with HIV remains a challenge to both the adolescent and guardian who is supposed to disclose the status. Some challenges that guardians face include fear that after disclosure, the adolescent may lose the will to live, judge them for getting HIV and they may also face family stigma (Vaz et al 2012:4).

As a result, most adolescents have learned about their HIV status late which could lead to poor treatment adherence and them not using condoms when they start being sexually active, therefore putting their sexual partners at risk of contracting HIV. Other adolescents have asked their guardians about their status after suspicions that they

could be living with HIV. There have been cases of non-disclosure, partial disclosure and full disclosure most of which occur much later than they should have (Mutumba et al 2015:473).

Partial disclosure refers to incomplete information that does not divulge the name of the disease while providing elements about what is happening on the adolescent and the need to take treatment (Wiener, Mellins, Marhefka & Battles 2007:4). On the contrary, full disclosure refers to disclosing all information about HIV, including mode of transmission and the need for lifelong ART (Wiener et al 2007:4).

Adolescents living with HIV form a significant proportion of people living with HIV in Swaziland. Despite this fact, there is not enough documented research for this unique population. Therefore, the study explored how ALHIV experience the process of disclosure so that their experiences are known and understood.

1.4 AIM OF THE STUDY

1.4.1 Research purpose

The purpose of the study was to understand the experiences of adolescents' (15-19 years) about their HIV status disclosure. This was done in order to have a clear understanding of the meanings adolescents have to help determine care and support services that are developmentally appropriate for them based on the findings of the study.

1.4.2 Research objectives

The objectives of the study were to

- explore and describe adolescents' experiences of their HIV status disclosure to them
- make recommendations based on the findings of the study on a suitable procedure to disclose to adolescents their HIV status

1.5 RESEARCH QUESTION

One grand tour question was used for the purpose of this study and the question was:

“What are the experiences of adolescents after their HIV status was disclosed to them?”

Participants then based probing questions on the responses as per the interview guide.

1.6 SIGNIFICANCE OF THE STUDY

The envisioned significance of the study is that it will assist policy makers and other relevant stakeholders to determine appropriate interventions aimed at improving the disclosure process to adolescents while also minimising stigma and discrimination towards adolescents living with HIV.

1.7 DEFINITION OF TERMS

1.7.1 Adolescence

Adolescence is the period of human growth and development that occurs after childhood and before adulthood, from ages 10-19 (UNICEF 2011). In the context of this study, an adolescent refers to a person between the ages of 15-19 years of age who is living with HIV.

1.7.2 Human Immunodeficiency Virus (HIV)

Human Immunodeficiency Virus (HIV) is a retrovirus that destroys the body's ability to fight off infection and disease, eventually causing AIDS (UNAIDS 2011:16). In this study, HIV is a retrovirus that destroys the body's ability to fight off infection and disease causing AIDS.

1.7.3 Acquired Immune Deficiency Syndrome (AIDS)

Acquired Immune Deficiency Syndrome (AIDS) is an epidemiological disease caused by HIV that is characterised by a wide range of clinical signs and symptoms (UNAIDS

2011:6). In this study, AIDS is an epidemiological disease caused by HIV that is characterised by a wide range of clinical signs and symptoms.

1.7.4 Anti-retroviral therapy (ART)

Anti-retroviral therapy (ART) is medical treatment, which consists of a combination of anti-retroviral drugs to maximally suppress the HIV virus and stop progression of HIV disease (UNAIDS 2011:7). In this study, ART refers to triple or more retroviral drug combination.

1.7.5 Experience

Experience is something that has happened to an individual that influences the way of thinking and behaving (*Oxford Advanced Learner's Dictionary* 2010:514). In this study, experience is an event that happens to an individual affecting them in the disclosure process

1.7.6 Disclosure

Disclosure refers to the act of a person living with HIV/AIDS sharing his or her status with others (Van Dyk, Tlou & Van Dyk 2017:146). For the purpose of this study, full disclosure refers to informing an adolescent about all facts regarding HIV infection, including treatment. Conversely, partial disclosure refers to giving limited facts and information about HIV infection to an adolescent living with HIV while withholding some information.

1.7.7 Caregiver

Caregiver refers to parents, family members or individuals caring for a child or adolescent living with HIV in a professional capacity (Aderomilehin, Hanciles-Amu & Ozoya 2016:2). In this study, caregiver refers to biological parents, adoptive parents, aunts, uncles, sisters, brothers and grandparents and any other individuals who may have a guardianship role over adolescents.

1.8 RESEARCH METHODOLOGY

Methodology is defined as the steps, strategies and procedures that are used to gather and analyse data in a study (Polit & Beck 2014:385). It gives guidance on which methods are best suited to the kind of research to be conducted. The study followed the qualitative paradigm that is concerned with quality of information and attempts to gain an understanding of the underlying reasons and motivations for actions and establish how people interpret their experiences and the world around them.

1.8.1 Research design

A research design is the plan and procedures of inquiry that span the decisions from broad assumptions to detailed methods of data collection, analysis and interpretation (Creswell 2014:3).

The study used a qualitative, explorative, descriptive design that was contextual in order to allow for deep understanding of the experiences of the adolescents of HIV status disclosure. The researcher opted for the qualitative approach because it seeks to understand and explore how individuals interpret and make sense of their personal experiences in the world in which they live. For this reason, the researcher believes that the qualitative approach was the most appropriate because critical truths about reality are grounded in people's lived experiences, in this case being adolescents living with HIV.

1.8.2 Sampling

Sampling is defined as the process of selecting a portion of the population to represent the entire population (Polit & Beck 2012:742). The researcher used purposive sampling which is a non-probability sampling method whereby the researcher selects participants based on personal judgement about which participants will be most informative (Babbie 2013:128).

The study population was adolescents living with HIV aged 15-19 years who already knew their status and were on ART. The research was conducted in two public clinics in the Hhohho region of Swaziland.

1.8.3 Data collection

Data collection is the process of acquiring subjects and collecting information to address a research problem (Burns & Grove 2011:361). The data were collected through in-depth individual semi-structured face-to-face interviews which were audio-taped and conducted by the researcher until data saturation was reached. There was no research assistant used in the data collection. An open-ended grand tour question asked was “What was your experience of HIV status disclosure?” The researcher prepared an interview guide and the first section of the interview guide captured respondents’ demographic data like age, gender and educational level. The home language Siswati was used to facilitate discussions. Other questions emanated from the main question above. The researcher took field notes and ensured that participants signed the assent forms before the commencement of interviews. The caregivers of these participants also gave consent for the adolescents to participate in the study.

1.8.4 Data analysis

Data analysis in qualitative research is non-numerical examination of text rather than numbers (Brink, Van der Walt & Van Rensburg 2014:193). The data were transcribed verbatim and later translated to English. Translated data was sent to the Siswati speaker to check that captured information had not lost the meaning. Transcripts were read sentence for sentence when coming back from the Siswati translator. To analyse data, Tesch’s qualitative data analysis approach was used with the following eight steps:

- First the researcher started with one document and while going through it, asked self ‘What is this about?’ The topic that came out clearly was written in the margin of the document.
- After completing this for several documents, the researcher made a list of all the topics and the topics were compared and similar topics were grouped together.
- Topics were then abbreviated as codes. With the list of codes, the researcher went back to the data and wrote the codes next to the appropriate segments of the text.

- The most descriptive words for the topics were identified, which had begun to turn into categories. Categories were reduced by grouping together those that relate to each other.
- A final decision was made on the abbreviation of each category in a way that ensured that no duplication occurs.
- Data belonging to each category was put together. The research question helped the researcher to discard irrelevant data.
- The existing data was recoded which helped the researcher give structure to the research report.

1.8.5 Data management

The participants were given pseudo names on the documents to ensure that their privacy was protected. Anonymity was ensured. This was to make it difficult to link any information to a particular respondent in future. These documents were only accessible to the researcher and were kept behind lock and key.

1.8.6 Trustworthiness of the study

1.8.6.1 Credibility

Credibility refers to confidence in the truth of the data and interpretations (Polit & Beck, 2014:323). It was ensured by intensely engaging the participants during the interview process and encouraging them to be open. Data collected among participants was compared and the researcher recorded day-to-day descriptions of the data collection process down.

1.8.6.2 Transferability

Transferability is the extent to which findings can be applicable to other settings (Polit & Beck 2014:323). To ensure transferability, the researcher provided sufficient descriptive data and a detailed descriptive context under which the study was undertaken, research methodology and accurate findings from the study which will enable replication in a similar context.

1.8.6.3 Dependability

Polit and Beck (2014:323) state that dependability refers to the reliability of data over time and over conditions. To ensure dependability, a pilot study was used to fine-tune the main study and bring up unanticipated problems. The pilot study also helped test the suitability of the interview schedule about the way questions were posed and probing. It was conducted on clients who met the inclusion criteria. The reader must be convinced that all steps taken by the researcher from the first to the last day of data collection actually happened; they must be clearly articulated transparently in a daily log.

1.8.6.4 Confirmability

Confirmability refers to objectivity about data accuracy, relevance and meaning without the researcher's imagination (Polit & Beck 2014:323). In this study, it was enhanced by the availability of raw data on the tape recorder and transcripts to verify themes with permission from participants. The researcher also took field notes.

1.9 ETHICAL CONSIDERATIONS

In order to reduce the risks of ethical violations during the research process, the researcher maintained ethical principles (as identified in Brink et al 2014:38). The ethical principles used were informed consent which is defined as a norm in which participants base their voluntary participation in research, with the full understanding of the possible risks involved (Babbie 2013:554). Confidentiality and protection of identity was also applied which states that a research study should guarantee confidentiality by stating that responses given by the participant will not be associated with a certain name. Moreover, privacy was adhered to whereby the participant was informed of the right to determine the extent to which private information would be shared with others. According to Brink et al (2014:36), justice refers to the participants' right to fair selection and treatment during the study. The ethical principles will be discussed in detail in chapter 3.

1.10 SCOPE OF THE STUDY

The study was conducted in one region of the country (Hhohho) in healthcare setups that are located in peri-urban areas of Swaziland in adolescents from the ages of 15-19 years who knew their status and were already on ART. The adolescents had peer group support. Regarding limitations of the study, it would have been better if adolescents from rural and marginalised communities were also part of the study in order to get a greater variety of perspectives. Adolescents living with HIV who were not enrolled on ART were excluded from the study because of the sampling method used. The study followed a qualitative approach and used semi-structured interviews as the primary method of data collection. Purposive sampling did not allow for a bigger number of research participants.

1.11 STRUCTURE OF THE DISSERTATION

Chapter 1: An overview and background of the study

Chapter 2: Literature review

Chapter 3: Research methodology

Chapter 4: Data analysis, presentation and description of the research findings

Chapter 5: Summary of findings, recommendations and conclusions

1.12 CONCLUSION

This chapter gives an overview of the research study “The experience of HIV status disclosure to adolescents in Hhohho region, Swaziland”. The researcher gave background information on the research topic internationally and in sub-Saharan Africa since there is no documented study in Swaziland. The next chapter will focus on literature review applicable to the study.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The previous chapter presented the study overview which covered background information about the research problem, statement of the research problem, aim and significance of the study, definition of terms, research methodology and ethical considerations applicable and the scope of the study. This chapter focuses on the global situation of adolescents living with HIV in sub-Saharan Africa, and specifically Swaziland. Scientific electronic sites like Google scholar and Pub Med with the key words (HIV, adolescents, disclosure and experiences) were used. These Internet search engines provided primary and secondary sources in the literature review, including peer-reviewed journals and policy documents on adolescents living with HIV. Brink et al (2014:70) state that a literature review is crucial and is conducted by the researcher for various reasons such as to conduct a critical analytical evaluation of recent scholarly work on the topic. The latter helps the researcher to obtain a comprehensive picture of the current state of knowledge. In addition, it is also important to place the study in the context of the general body of knowledge so that the new study makes a valuable contribution.

In order to conduct the literature review for this study, the search of the literature was trimmed to focus on the following key concepts of the topics below as they form the basis for the study; and each topic is discussed in the paragraphs below:

In order to conduct the literature review for this study, the search of the literature was trimmed to focus on the following key concepts of the topics below as they form the basis for the study; and each topic is discussed in the paragraphs below:

- Adolescents living with HIV in SSA.
- Disclosure of HIV status to adolescents.
- Adolescents' disclosure of their HIV status.

- Mental health issues of adolescents living with HIV.
- Sexual and reproductive issues in adolescents living with HIV.

Literature was reviewed using the following scientific websites: Google scholar, Pub Med as well as the library books that had the relevant information. Articles that were included in the review were based on the inclusion criteria of adolescents living with HIV.

2.2 ADOLESCENTS LIVING WITH HIV IN SUB-SAHARAN AFRICA

An estimated 36.7 million people were living with HIV worldwide in 2015 and out of this number, 17.8 million were women and girls (UNICEF 2016:14). In the same year, there were 110,000 AIDS-related deaths in children under 15 years of age, with 91,000 of these deaths in SSA (UNICEF 2016:14). Geographically SSA is the area in the continent of Africa that lies south of the Saharan desert and is known to be one of the under-developed regions of the world. The toll of HIV/AIDS continues to be harsh in this region, especially Southern Africa which remains heavily affected by the pandemic.

Adolescents make up the greatest proportion of the population in SSA. The latter is the only region of the world in which the number of young people continues to grow substantially (United Nations Population Fund 2012:8). Adolescents in SSA are also caught up in the pandemic as of the estimated 3.2 million adolescents under 15 years living with HIV, approximately 91% reside in SSA region. Between the year 2005 and 2012, estimated AIDS-related deaths among adolescents increased by 50% in SSA. It is also estimated that countries with the highest HIV burden of children from 0-14 years in SSA were South Africa (340 000), Tanzania (250 000), Mozambique (160 000), Uganda (150 000) and Malawi (130 000) (Stephen Lewis Foundation 2015c:3).

According to Lowenthal, Bakeera-Kitaka, Marukutira, Chapman, Goldrath and Ferrand (2014:1), the growing population of adolescents living with HIV infection within SSA presents not only unique challenges but also opportunities to learn further about HIV infection. AIDS-related deaths are declining rapidly for all age groups except adolescents (UNICEF 2014:7). AIDS remains the number one killer of adolescents in Africa and the second leading cause of death among adolescents worldwide. The number of adolescents living with HIV in Swaziland is about 19 000 and out of this

number, the percentage of adolescents aged 15-19 who were receiving ART in 2014 was 51% (UNICEF 2014:14).

2.3 DISCLOSURE OF HIV STATUS TO ADOLESCENTS

Over the last 15 years, there has been about 35% decrease in global HIV infections and a 58% decrease among children; yet more than 54% of children currently infected may be unaware they have the disease (Aderomilehin et al 2016:2). Disclosure of HIV status is one of the most complex challenges facing anyone living with HIV/AIDS because it involves communicating about a life threatening and stigmatised condition (Kiwanuka, Mulogo & Haberer 2014:1). Furthermore, disclosure of HIV status to adolescents is dependent on a complex variety of factors such as guilt, fear, stigmatisation, and isolation (Kenu, Abo-Akwa, Nuamah, Brefo, Sam & Larney 2014:1). Furthermore, HIV disclosure practices in SSA remain complex owing to the enormous impact of culture and limited HIV surveillance.

WHO's guidelines recommend disclosure to adolescents of their own status but prior counselling on potential benefits and risks of disclosure should be done (World Health Organization 2013:4). In addition, WHO advocates that disclosure should be done progressively to accommodate cognitive skills and emotional development. As Kenu et al (2014:2) suggest, telling adolescents about their HIV infection is a dilemma because they are often asymptomatic in the early stages of infection while they require daily medication and close monitoring.

2.3.1 Barriers to disclosure

2.3.1.1 Social stigmatisation

According to Mburu et al (2014:6), some of the barriers to disclosure include local norms that discourage parents and caregivers from communicating with their children about sexuality, fear of HIV stigma and an underlying presumption that adolescents would not understand the consequences of an HIV diagnosis on their lives and relationships.

Caregivers have also admitted to being reluctant in disclosing HIV status to their children because they fear social rejection and isolation, have a parental sense of guilt and fear that the children would not be able to keep the diagnosis to themselves and would be angry at them (Kenu et al 2014:2; Kiwanuka et al 2014:2).

A study conducted in South Africa by Moodley, Myer, Michaels and Cotton (2006:202) also reveal that caregivers were afraid of the child discussing his or her HIV infection with other people, especially with friends or children at school and neighbours in the community. According to Demmer (2012:2), stigma to HIV/AIDS among South African society made disclosure of the child's HIV status difficult because there was concern about the reaction of partners and family members which made women caregivers afraid of being blamed and abandoned.

Caregivers requested to be counselled first by health care practitioners (HCP's) before they could disclose results. This is because they felt that they lacked proper skills and knowledge that would enable them to disclose HIV status adequately and the fact that they treated disclosure as a once off event rather than as a process (Watermeyer 2013:591).

2.3.1.2 Health care practitioners

There is limited research in SSA on HCP's perceptions of how disclosure should happen. However, a few studies have been conducted in South Africa and Zimbabwe.

In a study conducted by Kidia et al (2014:3), HCP's explained that they did not have enough time to spend with each child because of the way the health system functions. Therefore, they felt caregivers should disclose the status to the child in the home environment initially, then they would reinforce and correct the information that was communicated by caregivers at home (Kidia et al 2014:3; Watermeyer 2013:593).

In a study conducted in South Africa, Madiba and Mokgathle (2015:9) reveal that HCP's pointed to lack of institutional guidelines as one of the reasons for non-disclosure as well as lack of training on the disclosure of HIV to children including on-going counselling and debriefing on how to deal with children living with HIV. Watermeyer (2013:593) further states that HCP's also highlighted the inconsistent nature of

disclosure practices at health care sites. While many of the HCP's were aware of the availability of various disclosure guidelines, tools and materials, these were not being implemented. Moreover, they mentioned the need for site-specific guidelines and policies regarding disclosure. In the same study, HCP's also expressed uncertainty about how to determine whether a child was in danger of self-harm after disclosure (Watermeyer 2013:594). The HCP's highlighted the case of an adolescent who had not yet been disclosed to, but found out about her status at the clinic by reading her clinic file and afterwards committed suicide. Still referring to the case, HCP's mentioned feelings of guilt as follows: *"We didn't do enough for her; we were not there for her; maybe we didn't pick up enough [of her distress] and maybe didn't support her enough"*.

To overcome this hurdle of non-disclosure, HCP's recommended that older and more experienced adolescents living with HIV should be engaged in disclosing to the younger adolescents using age appropriate terminology especially because they could also relate to them socially outside the clinic setup (Kidia et al 2014:5).

According to Watermeyer (2013:596), HCP's felt reluctant to overrule a caregiver's decisions about disclosure to the caregiver's child if the caregiver insisted on non-disclosure. They were worried about cases of litigation by the caregivers if they did something that they felt was not theirs to decide upon. The different cadres of HCP's also task shifted, with Counsellors and Nurses thinking it was the Medical Officer's prerogative to disclose while Medical Officers also felt the other team members were not actively initiating disclosure.

2.3.2 Factors contributing to disclosure

There are factors that contribute to the way disclosure of HIV status to the teenager should be handled. Several studies have identified these factors as they are discussed in the paragraphs that follow. In a study conducted by Mahloko and Madiba (2012:4), the most common facilitator was the children not adhering to treatment and the thinking that disclosure of the status would make the children adhere to treatment. Caregivers also disclosed because of fear that the children would learn the HIV diagnosis from other sources.

A SSA study conducted by Aderomilehin et al (2016:3) reveal that caregivers felt compelled to reveal status because of the availability of ART and that it was the right of the adolescent to know their status. Another factor that contributed to disclosure was constant inquiries by the adolescent living with HIV on why they had to attend the clinic regularly because of chronic illness.

According to Moodley et al (2006:202), about 98% of caregivers felt that the child has a right to know his or her own HIV status, and about 90% asserted that disclosure enhanced the child's mental health. On the contrary, 70% of caregivers said that the availability of ART made it necessary to discuss the child's HIV status with him or her.

In a study conducted in Uganda by Kiwanuka et al (2014:4), caregivers felt that children and adolescents living with HIV needed to know their HIV status to make sense of whatever was going on in their lives, especially in terms of their health. This would also motivate them to take ART consistently and take personal responsibility for their care while taking deliberate actions to protecting playmates and potential sexual partners, from accidental exposure to HIV.

In a study conducted in Tanzania, Mumburi, Hamel, Philemon, Kapanda and Msuya (2014:3) found several reasons for disclosure by parents/caregivers. They include the observation that the child was becoming suspicious owing to regular clinic attendances, and started inquiring about the nature of illness, the child being very sick, and the death of biological parents.

2.3.3 Outcomes of HIV disclosure

The disclosure of the HIV status has some expected and unexpected outcomes as it was the findings in the studies conducted about the HIV disclosure. In a study conducted in Malawi, findings revealed that some children were worried following the HIV disclosure because they were made to take the medication without knowing what was wrong with them. Some children felt that it would have been better if they had been told the diagnosis before starting medications instead of being made to take pills without giving any reasons (Phuma-Ngayiyaye & Dartey 2015:4). Another adolescent from the same study stated that she felt pain over the lifelong medications because she did not want to spend her life taking medications. In addition, she had fears of being

stigmatised by friends if the diagnosis was known to others, while another adolescent wondered why this happened to her instead of someone else (Phuma-Ngayiyaye & Dartey 2015:4).

In Uganda, there were varied reactions to disclosure. Several adolescents reported contemplating suicide after disclosure, ascribing their reactions to feelings of hopelessness and bitterness about their status, and simply wanting to die. Few adolescents reported a neutral reaction stating that they felt nothing after learning their HIV status, while a minority of participants reported positive reactions such as relief and happiness at learning the cause of their illness or knowing the family secrets (Mutumba et al 2015:478).

Gachanga and Burkholder (2016:15) stated the following outcomes of adolescents following disclosure, drop in school performance, disrespect, and anger towards parents for passing on the HIV to them. Older children who received full disclosure also experienced increased stress from keeping the illness a secret from younger siblings. Based on the above information, it can be concluded that disclosure does bring negative emotions to the adolescents

2.4 ADOLESCENTS' DISCLOSURE OF THEIR HIV STATUS

Madiba and Mokgatle (2016:2) argue that self-disclosure among adolescents living with HIV is a complex and difficult decision. Therefore, they are often reluctant to disclose their status for fear of rejection, stigmatisation, negative reactions, and responses. As a result, they put more effort into maintaining the secrecy of their status and want to have control regarding people to whom they disclose their status. Determining who should know about their status and choosing when and how to disclose may help adolescents feel empowered and self-sufficient.

Mburu et al (2014:4) opine that in as much as adolescents wished to practice autonomy over who knew about their status, at times they felt that was not always possible as household members were always aware of their status. This was evidenced by the quotation from the same study where one adolescent participant wondered how he could hide his HIV status from his younger sister when she was the one who accompanied him to the clinic. In addition, adolescents reported that they were aware of

the secret nature of their HIV diagnosis which is why they did not feel the need to disclose their status. They further remarked that HIV is an issue they do not commonly talk about with their friends at school despite that they spent a significant amount of time at school. Conversely, they were able to disclose to their friends at community centres because they felt connected to them and they enjoyed good interpersonal relationships since they went there for the same purpose (Mburu et al 2014:5). Fear of being gossiped about and stigmatised was an important consideration for keeping their HIV status a secret. This fear of adolescents to disclose their status to others also impacted romantic relationships whereby sexual partners were not disclosed to owing to fear of abandonment and rejection that poses a threat to onward sexual transmission of HIV to previously uninfected partners (Mburu et al 2014:7). However, other adolescents conceded that they could tell those close to them especially close family members because they felt they could trust them not to tell anyone, and that they actually supported them by reminding them to take their medications correctly while providing emotional support (Mburu et al 2014:6).

2.5 MENTAL HEALTH ISSUES OF ADOLESCENTS LIVING WITH HIV

A report by SHM Foundation (2014:5) reveals that until recently, most of the focus has been on the biomedical outcomes of HIV but there is growing awareness that many adolescents living with HIV are at increased risk of mental health problems which in turn leads to issues of treatment adherence. Good adherence to ART by adolescents living with HIV has been linked to adequate psychological adjustment, effective coping mechanisms, discussion, and adoption of clear medication routines.

An HIV diagnosis can have a longstanding negative impact on an adolescent's mental health. The SHM Foundation (2014:7) states that despite nationwide campaigns to raise awareness of HIV/AIDS and treatment options, levels of stigma and discrimination remain high in society. A substantial number of adolescents take the decision to travel long hours to go to clinics outside of their communities for their treatment because they do not want to go to the nearest clinic for fear of their status being disclosed to significant others and their community.

Levels of social isolation can therefore be very high for adolescents living with HIV, leaving them in the position where they do not feel comfortable sharing their concerns

or challenges with others. More importantly, the formation of support groups becomes crucial for ALHIV to provide the opportunity for exploring feelings and sharing ideas and experiences in a safe environment (Family Health International 360, 2013:28). A well-established referral network is vital to meeting the needs of ALHIV and maintaining contact with those who require on-going support.

It is reported by Fick (2014:14) that adolescents living with HIV also have to deal with issues related to disclosure and may have had multiple losses resulting in orphan hood, chronic illness, peer pressure, and the desire to “fit in” while also striving for autonomy. Depression and anxiety are common in ALHIV and are risk factors for suicide which may be missed. These signs could present differently than in an adult with depression. In addition, alcohol and substance abuse often co-exist with other mental health problems and raise concern for effects on ART adherence and may also be a risk factor for risky sexual behaviour or place adolescents at risk of violence. Adolescents with neuro-cognitive disorders can display slowness at processing information and this can be evident in concentration, attention, memory, learning, and higher-level functioning such as planning, judgement and organisation. There may also be abnormal motor skills or sensory perception together with school difficulty and learning problems because of these effects (Fick 2014:23).

2.6 SEXUAL AND REPRODUCTIVE ISSUES OF ADOLESCENTS LIVING WITH HIV

Adolescent sexual and reproductive health is an important issue in SSA given the generalised AIDS epidemic that has taken hold in many countries (Bankole, Biddlecom, Guiella, Singh & Zulu 2008:1). The rights of ALHIV to adequate psychosocial care and support and HIV and Sexual and Reproductive Health services are not realised and their needs remain largely unmet in low-income settings (Ross & Cataldo 2010:1). These authors further caution that adolescence is the period where young people often experiment with sexuality and drugs. Sexual activity is often initiated during adolescence, with risk taking and experimentation being considered normal by adolescents. After an adolescent is informed about HIV status, disclosure, safer sex and family planning become pressing issues. This happens without the adolescents taking necessary HIV preventative measures thereby increasing the risk of HIV infection to potential sexual partners.

In a study conducted in South Africa, Toska, Cluver, Hodes and Kidia (2015:47) reveal that negotiating safe sexual practices is particularly challenging for ALHIV and it is exacerbated by HIV-related factors, which entail learning and accepting their status. Among the sexually active adolescents, there was a basic understanding of living with HIV, modes of infection and transmission. However, this understanding did not always ensure safe sex or mutual disclosure of HIV-status between adolescents and partners (Toska et al 2015:54). One female adolescent in the same study was quoted as saying this:

“Once you have told that guy [that you are HIV-positive], he will sleep with you, and when he is finished with you he will just dump you like nothing has happened. His friend will want you as well, but that boy will tell him, “No, I’m finished everything there; so, there’s nothing left for you.”

Toska et al (2015:54) further state that adolescents who knew their status attempted to use condom with their partners, but though higher than among those who did not know their status, condom use was still inconsistent and subject to difficult negotiations. Disclosure of HIV-positive status to partners rendered adolescents vulnerable to abandonment and in return for sustained sexual and romantic intimacy and desirability, adolescents were less able or willing to insist on condom use and that disclosure of HIV-status to partners was not a priority. What the adolescents deemed important was the prevention of pregnancy and the avoidance of HIV-related stigma and rejection above HIV disclosure, particularly within casual relationships (Toska et al 2015:55).

According to Birungi (2009:6), ALHIV have the same Sexual Reproductive Health needs as other adolescents and do not lose their desire for sex or to have families because of their status. Even those adolescents who may not yet be sexually active do plan to be sexually active and have children in future.

2.7 CONCLUSION

This chapter on literature review emphasised studies that have been done in ALHIV in SSA. The literature review exposed that a few studies have been done on ALHIV in SSA with no documented study in Swaziland. The following chapter will focus on research design and methodology, data collection, and trustworthiness of the study.

CHAPTER 3

RESEARCH DESIGN AND METHOD

3.1 INTRODUCTION

The previous chapter presented and discussed literature review pertaining adolescents living with HIV in the global, SSA and Swaziland contexts. This chapter describes the research design and methodology utilised to understand the experiences of adolescents after HIV status disclosure. It describes the study population, which was 10 adolescents who volunteered to participate, sample and sampling technique used, data collection techniques, data collection instrument, data collection process, data analysis and the ethical considerations that the researcher employed during the research process.

3.2 RESEARCH DESIGN

Research design is an overall plan for addressing a research question, including specifications for enhancing the study's integrity (Polit & Beck 2014:390). According to Creswell (2014:3), a research design is the strategy and procedures for research that span the decisions from broad assumptions to detailed methods of data collection and analysis. Research design is the structured approach followed by researchers to answer a research question. This study used a qualitative, explorative and descriptive design that was contextual to allow for deep understanding of the experiences of the adolescents after HIV status disclosure.

3.2.1 Qualitative design

In this study, the qualitative design was used and according to Brink et al (2014:121), citing Babbie and Mouton, the goal of qualitative research is to understand rather than explanation and prediction. Characteristics of qualitative research design include flexibility and the capability of the researcher to adjust to what is learned during data collection, being holistic and understanding of the whole as well as requiring the researcher to be intensely involved (Polit & Beck 2014: 266).

Furthermore, Brink et al (2014:121) assert that key features of qualitative research are that it focuses more on the process, and less on the product. Moreover, the focus is not to generalise findings but to understand them in context and that the research is usually inductive in nature thus generating more questions.

3.2.2 Exploratory design

According to Grove, Burns and Gray (2013:694), an exploratory design is intended to increase the knowledge of a field of study and not intended for generalisation to a larger population. This study used an exploratory design to allow for deep understanding of experiences of ALHIV. The researcher used the exploratory design to gain insight on how ALHIV felt after status disclosure.

3.2.3 Descriptive design

Brink et al (2014:112) state that a descriptive design provides a picture of a phenomenon as it occurs naturally by describing variables to answer the research question. They further assert that the descriptive design is concerned with gathering information from a segment of a population.

3.3 RESEARCH METHOD

Methodology is defined as the steps, strategies and procedures that are used to gather and analyse data in a study (Polit & Beck 2014:385). This section describes the study setting, population, sample and sample size, method of data collection, and data analysis.

3.3.1 Population

A population is the group of persons that is of interest to the researcher, and those who meet the criteria that the researcher wishes to study (Brink et al 2014:131). Researchers seldom have access to the entire population they wish to study but are only able to study the accessible population. The target population in this study was ALHIV aged 15–19 years who already knew their status and were taking ART. The clinics where data were collected offer curative, family planning, antenatal care, child

welfare, and ART/TB services. At the first public clinic, about 100 patients are seen on a daily basis, 550 weekly and about 2000 monthly. The approximated number of adolescents attended per month is 40 and the sample for this study was determined from this population as described above. At the second public clinic, 190 patients are attended daily, 950 per week and 3800 per month. The approximated number of adolescents attended per month is 30 and the sample for this study was also determined from this population.

3.3.2 Sampling technique

Sampling refers to the researcher's method of choosing the sample from a population to obtain information regarding a phenomenon in a manner that represents the population of interest (Brink et al 2014:132). In addition, Polit and Beck (2012:742) define sampling as the process of selecting a portion of the population to represent the entire population. The researcher used non-probability sampling whereby participants were chosen by non-random methods, therefore making every participant not to have an equal chance of being included in the study (Polit & Beck 2014:178). According to Brink et al (2014:139), non-probability sampling places a greater burden of judgement on the researcher which can lead to bias and the research findings cannot be generalised to the entire population.

Purposive sampling, which is a non-probability sampling technique, was used whereby the researcher selected participants based on personal judgement about which participants would be most informative (Babbie 2013:128). The advantage of purposive sampling is that it permits the researcher to select the sample based on the knowledge of the topic being studied. For this study, the sample was obtained from the database and registers for all adolescents between the ages 15-19 who are on ART at the two public clinics.

3.3.3 Research setting

The study was conducted in two public clinics situated in Hhohho Region. The first public clinic is located in a peri-urban area and was officially opened in December 2006. It is funded by the Government of Swaziland and about 100 patients are attended to on a daily basis, 550 are attended weekly and about 2000 are attended to monthly. Other

participants came from the second public clinic that started operating in 2007. The clinic is also situated in a peri-urban area and is busy as the number of patients seen from the various departments at the clinic is 190 daily, 950 per week and 3800 per month.

A total of 171,266 people were currently active on ART by December 2016 in Swaziland. Out of those active, 45,730 were recorded from the Hhohho Region (Swaziland Ministry of Health Hhohho Regional Health Performance Report 2016:20). From this number, a total of 4004 adolescents in the age group 15-19 years were active recipients of ART during the same period (Swaziland Ministry of Health HIV Program Annual Report 2016:35).

3.3.4 Sample size

Polit and Beck (2014:181) posit that a sample size is the number of study participants required to answer the research question. Jacobsen (2012:117) further states that an adequate number of study participants is needed to reach valid and significant results. In this study, the sample size was determined by data saturation. Ten adolescents volunteered to participate in the study and their parents or guardians did not accompany any of them.

3.3.4.1 Sample

Polit and Beck (2014:391) define a sample as the sub-group of a population selected to participate in a study. The sample in this study was drawn from ALHIV who were aged 15–19 years and were receiving ART in two public clinics. Participants were eligible to participate in this study if they met all the inclusion criteria and were willing to participate. It was emphasised that participants must have signed an adolescent assent form and the caregiver signed the consent form before the data could be collected. The sample size was not fixed prior to data collection but it was determined by data saturation that was reached after the researcher had collected data from 10 participants (six females and four males).

3.3.5 Data collection approach

Data collection is the process of choosing and gathering data from the participants (Grove et al 2013:523). Steps involved in data collection are specific to each study and depend on the research design and measurement methods. The data were collected through in-depth individual semi structured face-to-face interviews. The researcher collected data by herself. The advantage of interviews is that they create rapport between the researcher and participant and indicate to the participant that the researcher is interested in understanding the experience being discussed (Brink et al 2014:158). The interview also allowed the researcher to observe non-verbal cues which were valuable for interpreting the participants' feelings towards certain questions and the responses they gave. These non-verbal communication cues were documented and assisted the researcher during data analysis.

The following open-ended grand tour question was asked during the interview “*What is your experience of HIV status disclosure?*” This grand tour question was also followed-up by probing questions for clarity and more understanding. The home language Siswati was used to collect data during discussions, which were facilitated by the researcher. Probing questions emanated from the one above. The researcher also took field notes and made it clear to participants that consent to be part of the study was voluntary and signing the assent form and that the researcher would need their caregiver's consent for them to participate in the study.

3.3.5.1 Data collection tool

According to Creswell (2014:185) in qualitative research, the researchers are the key instrument since they collect data themselves. In this study, the researcher who also observed behaviour while conducting the interviews collected the data. An interview guide was developed (see annexure D) which started with an open-ended grand tour question “*What is your experience of HIV status disclosure?*” The researcher then probed where necessary to get clarification based on the responses of the participants.

During the interview, the researcher asked few specific questions and additional probes for clarity (Brink et al 2014:158). In conducting face-to-face interviews, the researcher needs to have experience to avoid influencing the outcome and bias control. A pilot

study was conducted for this research where two interviews were held with participants who met the inclusion criteria. The pilot study was used to test if there would be any need for the adjustment of the instrument. Consequently, the pilot study showed that there was no need to do any adjustment to the interview guide as it yielded what the researcher expected to achieve.

3.3.5.2 Data collection process

After getting permission to conduct the study from the University of South Africa (Unisa) Higher Degrees Ethics Committee (see annexure E) and the Swaziland National Research Review Board (see annexure F), the researcher met with the clinic Manager and staff where they were informed about the study during a short meeting. The researcher explained the aims and objectives of the study as well as the inclusion/exclusion criteria of targeted participants. Prior to commencement of the study, the staff as well as the researcher sensitised the participants that met inclusion criteria. Accordingly, the researcher was introduced to the participants and given an opportunity to present the study and informed them about their rights as participants. Participants were also informed that taking part in the study meant they would be interviewed about their personal experiences of HIV status disclosure. More importantly, the researcher also made it clear that their consent to be part of the study was voluntary and that their caregiver's consent was also needed for the ethical considerations. Participants were reminded about the set appointment by calling them the day before.

On the day agreed upon with the participants, the researcher was allocated a room that provided privacy in which to conduct the interviews. The **“Do not disturb”** sign was put on the door and there was no telephone. Participants gave verbal consent and signed assent forms before the interviews commenced. Interviews lasted between 30 – 40 minutes and were conducted in Siswati, as all participants were comfortable being interviewed in Siswati. The interviews conducted were face-to-face, which allowed the researcher an opportunity to observe other important factors such as general appearance, overall health and non-verbal behaviour. The researcher had an interview guide that provided some control over the interview process and ensured uniformity during the interviews. Permission to audiotape the interview was asked from participants. A social worker was available to offer emotional support in case the participants could not handle the interview well.

A pocket-sized audio-recorder was used to record all the interviews with the permission of the participants. The researcher took field notes to guarantee accuracy and clarity during transcription of the interviews, without leaving out vital information during the interviews, such as how participants responded and reacted to the questions asked.

The researcher utilised intuition during the data collection process whereby there was an awareness of the lived experience and being open to the meaning that participants attached to the subject discussed and being totally engrossed in that subject, aided by the participants' descriptions (Brink et al 2014:122). Once data saturation was reached, interviews were stopped.

3.3.5.3 *Data saturation*

Data saturation is the point at which new data no longer emerge during the data collection process (Brink et al 2014:141). Data saturation occurs when additional participants do not provide new information, but only redundancy of data collected and when themes that emerge become repetitive (Burns & Grove 2011:317). The sample is then said to be satisfactory and the data are considered thick and rich (Brink et al 2014:173). In this study, data saturation was reached after the researcher had collected data from 10 participants (six females and four males). None of the adolescents was accompanied by caregivers. After data were collected and saturation was reached, the analysis followed as discussed below.

3.3.6 Data analysis

Data analysis in qualitative research is the non-numerical examination and interpretation of text rather than numbers with the aim of eliciting underlying meanings (Brink et al 2014:193; Babbie 2013:389). To analyse the audio-recorded interviews, Tesch's qualitative data analysis approach (cited in Creswell 2014:198) was used with the following steps:

After data collection, the researcher typed the field notes of all the interviews. The data were transcribed verbatim and later translated to English. Translated data was sent to the Siswati speaker to check if captured information had not lost meaning. For analysis,

the first step was reading the entire transcripts sentence for sentence until the researcher became familiar with the data.

The second step was identifying specific topics in the interviews. The researcher started with one document and went through it with the intention of looking at the underlying meaning more than the substance of information. Topics that came up were noted on the margin of the transcript. The researcher repeated the above with all the interviews conducted and then made a list of all topics that came up from the several participants' interviews. Thirdly, similar topics were then clustered together according to similarity and were then abbreviated as codes. The fourth step was for the researcher to go back to the data with the list of codes and write them next to the text under which they belonged. This led to the emergence of new categories(sub-themes), namely: fear of death, sickness, loss of parents, knowing own HIV status, self - disclosure, keeping the secret, disclosure setting, family support, teen club membership, and taking ART. A final decision was made by the researcher on the abbreviation of each category using the first and last alphabets of the categories, for example, FH, SS, LS, KS, SE, KT, DG, FT, TP, and TT. The categories were further reduced by grouping together those topics that relate to each other leading to three main themes, namely, living with HIV infection; disclosure of HIV status; and coping with HIV. The research question helped the researcher to discard irrelevant data. The themes were developed with the aim of answering the research question. All the above steps helped the researcher give structure to the research report. Themes that emerged in data analysis are discussed further in chapter 4.

3.4 TRUSTWORTHINESS

Establishing the trustworthiness of a research study gives assurance that the research instruments were proficient in providing accurate and meaningful answers to the research questions. Trustworthiness of this study was enhanced by using the four criteria of trustworthiness credibility, dependability, confirmability, and transferability proposed by Lincoln and Guba's model.

3.4.1 Credibility

Credibility refers to confidence in the truth of the data and interpretations (Polit & Beck 2014:323). In this study, credibility was ensured by prolonging engagement and intensely engaging the participants until data saturation was reached (Babbie & Mouton 2011:277). During the interview process, participants were encouraged to be open. An interview guide was used and field notes were also taken to capture non-verbal responses of participants. Data collected among participants were compared and the researcher recorded day-to-day descriptions of the data collection process.

Babbie and Mouton (2011:275) argue that extensive field notes also ensure credibility. The researcher kept two sets of notes, which described the environment where the research was conducted and the other set of notes containing observations which enhanced or contradicted original ideas. These set of notes were continuously referred to in order to adjust the research design as research continued should there be a need.

3.4.2 Transferability

Transferability is the extent to which findings can be applicable to other settings (Polit & Beck 2014:323). To ensure transferability, the researcher provided sufficient descriptive data and a detailed descriptive context under which the study was undertaken, research methodology and accurate findings from the study, which will enable replication in a similar context. Purposive sampling was used to maximise the range of specific information that could be obtained by purposely selecting participants from different locations and who differed from one another (Babbie & Mouton 2011:277).

3.4.3 Dependability

Polit and Beck (2014:323) postulate that dependability refers to the reliability of data over time and over conditions. It is vital that there is evidence that if a study was to be repeated with the same participants under the same context, the findings would be the same (Babbie & Mouton 2011:278). To ensure dependability, a pilot study was used to fine-tune the main study and bring up unanticipated problems. The pilot study also helped test the suitability of the interview schedule about the way questions were posed and the degree of probing needed. It was conducted on clients who met the inclusion

criteria. A clearly articulated daily log was used so that the reader could be convinced that all steps taken by the researcher from the first to the last day of data collection actually happened.

3.4.4 Confirmability

Confirmability refers to objectivity about data accuracy, relevance and meaning without the researcher's imagination (Polit & Beck 2014:323). According to Babbie and Mouton (2011:278), confirmability is the extent to which findings are the product of the focus of inquiry and not biases from the researcher. In this study, it was enhanced by the availability of raw data on the tape recorder and transcripts to verify themes with permission from participants. Data reconstruction and synthesis of developed themes were also reviewed.

3.4.5 Ethical considerations

To reduce the risks of ethical violations during the research process, the researcher maintained ethical principles (Brink et al 2014:38). A consideration of ethical issues is necessary in any research involving human subjects and especially when working with minors. The study was conducted only after getting clearance from the Unisa Higher Degrees Ethics Committee (see annexure E) and the Swaziland National Research Review Board (see annexure F).

Permission to conduct the study

The researcher got ethical clearance from the Unisa Higher Degrees Ethics Committee (see annexure E) and the Swaziland National Research Review Board (see annexure F). A letter was written to the clinic Manager of the chosen research site requesting to conduct a study. The letter was hand delivered to the institution together with ethical clearance certificate and permission from Swaziland National Research Review Board.

Informed consent

Informed consent is a norm in which participants base their voluntary participation in research, with the full understanding of the possible risks involved (Babbie 2013:554).

According to Polit and Beck (2014:87), informed consent means that participants have adequate information about the study and comprehend the information, and have the power to choose freely if they want to participate or decline participation voluntarily.

Informed consent has three major elements namely, the type of information needed from the participant; the degree of understanding that the participant must have to give consent; and that participation is voluntary (Brink et al 2014:38). In this study, all these three elements were adhered to by the researcher as evidenced by the inclusion of information and consent forms for caregivers (see annexure B) and information and assent forms for the adolescents (see annexure C).

Avoidance of harm (non-maleficence)

Participants were protected against emotional and physical harm, within reasonable limits. The potential risks were emotional, rather than physical and they arose from the participants being asked to recount painful experiences about disclosure of their HIV status. When this happened, the researcher calmed them down and paused the interview briefly.

Confidentiality and protection of identity

Confidentiality was of utmost importance in the study and was guaranteed by stating that responses given by the participant would not be associated with a certain name. The researcher kept the data collected confidential and anonymous and used them only for the purposes of the study. The researcher allocated pseudonyms to the participants to protect their identity

Justice

This principle refers to the participants' right to fair selection and treatment (Brink et al 2014:36). During selection of participants, the researcher should select fairly from the accessible population and in this study, selected participants were related to the research problem not because they were easy to reach. During the research process, all participants were treated the same way and a bus fare refund was given since the participants could not afford it on their own.

3.5 CONCLUSION

In this chapter, the research methodology was described, detailing how the research was conducted. The research was based on a qualitative approach and utilised an exploratory descriptive design. Purposive sampling was used to select recruits and individual semi-structured interviews were used to collect data. Interviews were audio taped and this was used as the main data source. Data were analysed using Tesch's qualitative data analysis approach. Trustworthiness was confirmed using Lincoln and Guba's model. Ethical considerations discussed included confidentiality, avoidance of harm, informed consent, and justice. The next chapter will discuss presentation and analysis of research results.

CHAPTER 4

DATA COLLECTION, ANALYSIS AND PRESENTATION OF FINDINGS

4.1 INTRODUCTION

The previous chapter presented the research design and methodology applied to understand the experiences of adolescents after HIV status disclosure. It described the study population, sample and sampling technique, data collection techniques, data collection instrument, data collection process, data analysis, and the ethical considerations employed during the research process. This chapter discusses and presents the findings of the study. The findings of the study are based on the analysis of the interview transcripts and the researcher's field notes on the experience of HIV status disclosure to adolescents in two public clinics in the Hhohho Region of Swaziland.

The findings are presented in this order: biographical information of the research participants, followed by themes and sub-themes that emerged during data analysis to answer the research question "What are the experiences of adolescents after their HIV status was disclosed to them?" These will be backed by quotations from participants for emphasis, where necessary. The research findings will be compared with literature review available on the topic.

4.2 DEMOGRAPHIC INFORMATION OF PARTICIPANTS

Ten adolescents (six females and four males) participated in this study. There were six participants from the first public clinic (four females and two males) and four participants from the second public clinic (two females and two males). All the participants were Swazi and were between the ages of 15–19 years. The mean age of the adolescents was 17 years. Biographical information of each participant is summarised below. Participants were allocated pseudonyms to protect their identity.

Bheki

Bheki is a 16-years-old boy who is doing Grade 10. He is a happy adolescent who looks healthy but small for his age. He lives with his biological mother, stepfather and three children who came into the relationship with the stepfather. He does not know where his biological father is. He is the first-born followed by two sisters who are 12 and nine years respectively. His mother disclosed his HIV status to him in 2010 when he was doing Grade 5. During that time, he was already taking ART and he does not remember exactly when he started taking it.

Neli

Neli is a 17-years-old girl who is doing Grade 10. She looks healthy but small for her age. She talks freely and expresses herself well. She stays with maternal grandparents and an uncle. Both parents are teachers and she does not stay with them but they visit her regularly. She is a second child and has two siblings, a brother who is 26 years old and a sister who is nine years. Her HIV status was disclosed to her when she was nine years old by her mother but she does not remember the year. During that time, she was already on ART but she had not noticed that she took medication daily.

Gugu

Gugu is a 15-years-old girl who is doing Grade 5. She is shy and cognitively slow. She stays with her biological mother, and four brothers and sisters together with her stepfather. She is the last-born. Her stepfather did not bring children to the marriage. She does not know her biological father and she was told he passed away. She stated that she was always sick; so, she was tested for HIV in 2014 and was then started on treatment. The doctor disclosed her HIV status to her at the hospital.

Sindi

She is reserved and looks healthy. She last attended school last year and was in Grade 6. She is at primary school because of recurrent hospitalisations that disrupted school and she has changed residences three times in her life. Her biological mother passed away in 2006. Her biological father is alive but last visited home in 2012. She stays with

paternal grandparents and two siblings from the father's side and she is the last-born. Her aunt disclosed her HIV status to her at home when she was 11 years old but she does not remember the exact year. When her status was disclosed to her, she was already taking ART.

Lusanda

Lusanda is an 18-years-old girl who is doing grade seven. She looks happy but has episodes of self-consciousness. She stated that when she was young she would get sick which resulted in her missing school. Both biological parents passed away when she was young. She had lived with her uncle and his family since 2011, which includes the wife and their four children. She has one brother who is 25 years old from the mother's side. She started taking ART in 2008 and her HIV status was disclosed to her after she was started on treatment.

Sanele

Sanele is a 19-years-old boy who is currently not schooling. He is stunted but otherwise looks healthy. He was attending a school for children with special needs last year but dropped out and he is doing part-time jobs. He lives with both biological parents and five siblings. He is the third born child. His HIV status was disclosed to him at the clinic in 2012 after he was tested because of recurring gastro-enteritis. In the same year, he started ART.

Joseph

Joseph is a 17 years old boy who is currently not at school. He last attended school in 2015 and was in Grade 6. He is not at school because when schools opened this year, he got sick with Tuberculosis. He lives with his biological mother and maternal grandparents and uncle. His father passed away when he was young. He is the first-born followed by four girls. His HIV status was disclosed to him when he was seven years old and already on treatment.

Zile

Zile is a 16-years-old girl who is in Grade 6. She looks healthy with no underlying health issues. She lives with both her biological parents and her younger sister. A nurse disclosed her HIV status to her in 2016 after she had gone for Voluntary Counselling and Testing (VCT). She decided to test because both her parents are living with HIV. She started ART in 2016 after testing for HIV.

Themba

Themba is a 15-years-old boy who is doing Grade 5. He took one year off school and stayed home in 2015 because of financial challenges. He has health issues which were evident because he looked emaciated. He is cognitively slow. He lives with both biological parents and maternal grandparents. He is the first-born child and has two younger sisters. He started ART in 2013 but was told of his HIV status in 2015 and the doctor disclosed his HIV status to her in the hospital.

Dudu

Dudu is a 16-years-old girl who is doing Grade 7. She looks healthy. She lives with her maternal grandmother. Her mother stays in another town with her stepfather. Her biological father stays in the same community but not with her family. She is the only child from her mother but has many siblings from her father. She was tested for HIV in 2015 but her status was hidden from her. Her grandmother encouraged her to join the local teen support group in 2016 and that is when she confirmed her status. She started ART in 2016.

All participants seemed to be older than their grades at school. This is a common occurrence among children and adolescents living with HIV in Swaziland owing to recurrent illnesses that take them away from school for long periods of time, leading to them repeating classes. Some of these adolescents were orphans and vulnerable. This necessitated the changing of residences after the death of parents as relatives accommodated them. This means they must move from one place to another, therefore changing schools in the process. The schooling system in Swaziland begins with pre-school, progresses to primary school, secondary school and exits at high school, which

is O' Level. Progression from one class to the next is through passing or promotion based on academic merit. Children who fail usually repeat classes but are sometimes promoted to the next grade based on their teacher's recommendations. All students are admitted to school regardless of the chronological age.

Data collection

The researcher collected data at the first clinic on 29 July 2017 and 5 August 2017. On 12 August 2017, data were collected at the second clinic. Ten participants were recruited and they comprised six females and four males. All the dates of the data collection fell on a Saturday since that was the day most suitable for the adolescents to come and not miss classes at school. Interviews began at 9 am and before they began, participants read and signed the information sheet and assent form. Caregiver consent forms were already signed on the day of the interview since the participants had been given the forms days before the interview. None of the caregivers accompanied their children for the data collection. The data were collected through in-depth individual semi-structured face-to-face interviews lasting approximately 30–40 minutes that were audio-recorded and were conducted in a quiet room to avoid disturbances.

The interviews were conducted in the home language (Siswati). During the interview, the researcher took field notes and non-verbal cues of the participants were observed and noted. During the data collection process, the participants were calm and there were no episodes of emotional upset, they were at ease and could talk about their HIV status without feeling awkward. After the interview, the researcher thanked participants and gave each E50 bus fare refund.

Data analysis

After data collection, the researcher typed the field notes and the 10 interviews. The data were transcribed verbatim and later translated to English. More importantly, translated data was sent to the Siswati speaker to check that captured information was accurate. All transcripts were read sentence for sentence until the researcher became familiar with the data. The next step was identifying specific topics in all the interviews. The topic that emerged was written on the margin of the transcript. The researcher repeated the above with all the interviews conducted and then made a list of all topics

that came up from the participants' interviews. Similar topics were then clustered together according to similarity and coded, thereafter categories emerged. Each category was abbreviated such that duplication was avoided. The categories were reduced by grouping together the topics that relate to each other to form broad themes, namely, living with HIV infection, disclosure of HIV status and coping with HIV. The themes were developed with the aim of answering the research question "*What are the experiences of adolescents after their HIV status was disclosed to them?*" A preliminary analysis was done and irrelevant information was eliminated.

4.3 EMERGING THEMES

Three key themes emerged during data analysis together with sub-themes. The themes and sub-themes are tabulated in the table underneath.

Table 4.1 Summary of themes and sub-themes

Themes	Sub-themes
Living with HIV infection	Fear of death Recurrent sickness Loss of parents owing to AIDS
Disclosure of HIV status	Knowing own status Self-disclosure Keeping the secret Disclosure setting
Coping with HIV	Support from family Teen club membership Taking ART

The above identified themes and sub-themes are discussed in the paragraphs that follow.

4.3.1 Theme 1: Living with HIV infection

Living with HIV is defined by UNAIDS (2011:23) as being infected with HIV and being able to live healthily and productively for many years without developing AIDS defining illnesses. This theme emerged from the participants because they were living with HIV, which is an incurable disease. Participants in this study felt that knowing they were

living with HIV was one of the most difficult situations they had to face in their lives and it brought negative reactions like disbelief, sadness, despair, and anger. Most of them were not sure how to move forward with their lives after this life-changing event. This theme gave rise to the following three sub-themes, namely, fear of death, recurrent sickness, and loss of parents owing to AIDS.

The following paragraphs will discuss the sub-themes as they appeared under theme one.

4.3.1.1 *Fear of death*

According to Wijedicks, Valeras, Gronseth and Greer (2010:1), death is defined as the irreversible cessation of circulatory and respiratory functions. This sub-theme emerged from participants based on the knowledge that people with HIV eventually die owing to progression of the infection, which eventually led to death. Four participants stated that they feared death owing to HIV infection immediately after disclosure but later on they accepted their new diagnosis and moved on and tried to incorporate HIV into their lives. However, from time to time they thought about living with HIV and that the ultimate consequence was death.

“The thought that came [to my mind] was I will also die soon and I asked my mother but she said I can live up to 70 years if I take care of myself.” (Bheki)

“After I was told of my status I thought I was going to die because I knew that if you have HIV you die.” (Neli)

“Sometimes I worry that eventually I will die from HIV.” (Sindi)

“Both my parents died, and I suspect now [that I understand] that it could be owing to HIV so there is always that fear.” (Lusanda)

The findings from the study are similar to a study conducted by Mavhu, Berwick, Chirawu, Makamba, Copas, Dirawo, Willis, Araya, Abas, Corbett, Mungofa, Laver and Cowan (2013:5) in Zimbabwe. The adolescents reported that knowing their status brought a sense of imminent death together with other unpleasant emotions. A South African study conducted by Jaspan, Li, Johnson and Bekker (2009:9) reiterates that

adolescents face exceptional and formidable challenges, among them, issues of life expectancy. The lifelong nature of HIV made it impossible for most participants to forget that they were living with HIV.

4.3.1.2 Recurrent sickness

Sickness is defined as the state of being physically or mentally ill (*Oxford Advanced Learner's Dictionary* 2010:747). This sub-theme emerged from the participants because all of them reported recurrent episodes of poor health while growing up and recently where some ended up being admitted for long periods of time for their ailments. This is also evident in that out of 10 participants, only two are in High school, the rest are still in primary school despite that their ages indicated they should be in higher grades. One participant was in a poor state of health during the interview and had healed chicken pox lesions and an abscess on the chin. The participants in this study had varied ailments, which included chronic diarrhoea, lung infections, convulsions, and dermatitis.

“When I was 11 years old, I got sick one Sunday afternoon and on Monday morning my grandmother found me having clots in my mouth. She took me to Hlatikulu Hospital where I was admitted for two weeks. After some time, I then got sick again and was taken to Hlatikulu Hospital for the second time.” (Sindi)

“In 2012 I was admitted at Hlatikulu hospital for six weeks because I had diarrhoea.” (Sanele)

“When schools opened this year, I got sick with TB and by the time I recovered, time had gone; so, I decided to start school next year.” (Joseph)

“In 2015, I was coughing continuously. My mother took me to hospital where they told her that I had pneumonia.” (Dudu)

These findings are supported by a previous study in SSA by Lowenthal et al (2014:3). The latter study reported that HIV infection in late childhood presents with multiple non-specific complaints including recurrent upper respiratory chest infections, diarrhoea, minor skin infections, and sub-optimum growth. Lowenthal et al (2014:6) further state that growth failure, stunting and pubertal delays generally distinguishes perinatally infected adolescents from those infected sexually together with those who are not

infected. This stunted growth becomes obvious during adolescence because this is a period of rapid growth and pubertal development. Catch-up growth can be attained after the start of ART. However, if ART is delayed, height potential is not regained.

4.3.1.3 Loss of parents owing to AIDS

This sub-theme came about because four of the participants have experienced the loss of one biological parent, whilst one participant reported to have lost both biological parents owing to AIDS. The participants expressed feeling sadness and pain after the death of parents. They also reported distress in seeing their parents sick.

“My mother passed away when I was eight years old. I cried on that day. She was sick for a long time but I don’t know what was wrong with her. I miss her. After some time my father got sick and also died.” (Lusanda)

“My father passed away when I was young and I don’t remember him too well.” (Joseph)

Previous similar studies conducted in Botswana and Tanzania state that many ALHIV have experienced the loss of parents and close family members. After the loss of a parent, adolescents worried who would take care of their financial needs and ensure that they continue attending school (Midtbo, Shirima, Skovdal & Daniel 2012:264, Mavhu et al 2013:4).

Two adolescents had to change residences after the death of parents, which was stressful as they had to adapt to new environments while grieving the loss of their parents.

“I started staying with my uncle in 2011. Before then I was staying with my sister in Nhlengano but I cannot go into detail [about that] because it’s complicated.” (Lusanda)

“Mom passed away in 2006. I don’t know my dad but he is alive. I was staying at my cousin’s place and now I stay in another homestead.” (Sindi)

The above findings concur with Mavhu et al (2013:4) that most ALHIV live in homes not headed by their mothers or fathers. They are prone to changing residences owing to the death of caregivers. At times, they are forced to move more than once to relatives who are willing to accommodate them.

4.3.2 Theme 2: Disclosure of HIV status

According to Sariah, Rugemalila, Somba, Minja, Makuchilo, Tarimo, Urassa and Siril (2016:1), disclosure is defined as a state in which a child has knowledge about his or her status. The theme disclosure of HIV status emerged when participants reported how they experienced disclosure from a viewpoint of knowing their status and also disclosing to others together with the feelings they underwent. Sub-themes that are under this theme are knowing own HIV status, self - disclosure, keeping the secret, and disclosure setting.

4.3.2.1 Knowing own HIV status

This sub-theme emerged from participants based on the research question that wanted to know if they knew their status and how they felt when their status was disclosed to them. All 10 participants knew their status at the time of the interview and the earliest age of disclosure was seven years while the latest age of disclosure was 15 years. The disclosure was done once and there were no follow-up disclosure sessions by HCP's or caregivers. For six of the adolescents, disclosure was necessitated by episodes of serious illness, which led to them being hospitalised.

"I knew my status when I was nine years old. My mother told me that it was discovered after I was born that I have HIV." (Neli)

"I got to know my status when my aunt told me. I was 11 years old at that time. She told me after my second [hospital] admission." (Sindi)

"I was told [of my status] when I was seven years old. At that time, I was young and didn't understand much. I got to understand as I grew older. It was in 2013 when I started understanding." (Joseph)

Three participants stated that their status was disclosed when they were already on treatment. When probed further they reported that they had not noticed that they were taking medication daily and they had not bothered to ask what the medication they were taking was for.

“I was attending the teen club for some time and then I asked my mother when we were at home, just the two of us what the tablets they were referring to at the clinic are for and she explained to me that I have HIV. After that explanation, I accepted because she told me a long time ago when I was in Grade 5.” (Bheki)

Several studies in SSA (Kallem, Renner, Ghebremichael and Paintsil 2011; Mahloko & Madiba 2012; Vaz et al 2012) have reported low levels of disclosure to children and adolescents about their status despite growing evidence of the benefits of disclosure. Caregivers do not disclose because of their belief that the child is too young to understand the implications of living with HIV and taking ART. According to Midtbo et al (2012:262), it is known that non-disclosure of HIV status to HIV infected children and adolescents is a barrier to them adhering to ART.

Vaz et al (2012:4) assert that caregivers do not disclose because they are concerned about causing psychological harm, fear social stigma, being judged and are usually unprepared to answer subsequent questions. Despite the caregivers' fears to disclose to children and adolescents about their HIV status, it was discovered that these children and adolescents improved ART adherence once they were disclosed to and had fewer emotional problems than those who had not been disclosed to (Midtbo et al 2012:262). Furthermore, when adolescents know their HIV status, they understand better the purpose of hospital check-ups and medication regimes which allows them to make sense of their lives (Midtbo et al 2012:265).

There were varied negative emotions that were felt by the adolescents after their status had been disclosed to them. There were no positive or neutral reactions to disclosure. For the participants, the most difficult time was the moment when they were informed that they had HIV as it proved to be devastating.

"I got angry and I was asking myself why my mother was telling me this now. I asked myself many questions like why me, why am I not [HIV] negative like my brother or sister. I also felt extremely sad." (Neli)

"When my aunt told me about my status, I felt sad...I cried for days. It seemed like my life had come to an end. I felt like nothing." (Lusanda)

"I felt disoriented, but I immediately stopped thinking about it because if I continued thinking about it I would be dead by now." (Sanele)

"After my mother told me I felt like stopping taking the treatment. I also asked why I was the only one who was affected as I'm the only one from my siblings who has HIV." (Joseph)

"I cried and then thought let me accept because both my parents are living with HIV and are on ART. Only my younger sister is negative." (Zile)

The above findings concur with similar studies conducted in South Africa and Zambia by Madiba and Mokgatle (2016:4) as well as Mburu et al (2014:6) that status disclosure brings about a variety of emotions like hurt, shock, anger, and confusion with some adolescents stating they felt they were dying during the disclosure event. Adolescents in these studies also experienced anxiety, depression and social withdrawal as reactions to disclosure.

4.3.2.2 Self-disclosure

Self-disclosure refers to the act of a person living with HIV/AIDS sharing his or her status with others (Van Dyk et al 2017:146). The sub-theme of self-disclosure emerged from participants after they were asked whether they had disclosed their status to others. All participants stressed that they could not disclose their status to anyone because of fear that they would be treated differently and they feared discrimination, rejection and stigma. Most of them were also worried that the story of them being sick would spread around their communities and that they would lose their friends if their status was known. Another reason for not disclosing was mistrust of their friends and the ability of the friends to keep their status confidential.

"I have not told anyone. I think that if I tell them they will treat me differently from others because I have HIV and start saying funny things. I don't trust my friends; we talk about everything else except HIV." (Neli)

"No one except my family knows that I have HIV. As people, we don't trust each other, you will tell one person and that person will also tell another resulting in the story spreading. Another reason is that people like to look down upon others, you will tell them and then one day when you greet them they will just look at you and not answer." (Sindi)

"My friends don't know. I don't trust people because you tell one person and then you will hear your story from other people. I even told my mother not to tell her friends about my status because I also didn't choose to have HIV." (Joseph)

"I will not tell anyone. They may say don't play with this one and don't eat her food; she will give you HIV. They may also stop being friends with me." (Zile)

The above findings resonate with a study conducted in Zambia by Mburu et al (2014:4) where adolescents felt that disclosure was a personal decision and that they should be allowed to decide to whom and when they disclose. Another study conducted in Zambia by Hodgson, Ross, Haamujompa and Gitau-Mburu (2012:4) reiterates that adolescents were not able to disclose because of lack of trust in their friends.

According to Midtbo et al (2012:261), children and ALHIV are subjected to gossip, discrimination and hostility because of their association with HIV, and the fear of these negative reactions from others affirms their intent to keep their status a secret.

Three participants were worried of assumptions regarding the transmission of HIV that are prevalent in society. They stated that if they disclosed their status to others, they would think they acquired the infection sexually and accuse them of being immoral and promiscuous and therefore personally responsible. Societal belief was that HIV is a sexually transmitted infection because they lacked knowledge and for that reason, they would not be free to disclose since that would lead to people stigmatising them.

“People will think it is my fault that I have HIV; they will say I am lying that I got it from my mother; so, it’s best they don’t know I have it”. (Dudu)

“No matter what I say, behind my back they will be talking, saying she was sleeping around that is why she has it”. (Neli)

The findings from this study are affirmed by a study conducted by Gachanja and Burkholder (2016:13), Madiba and Mokgatle (2016:5). In the latter studies, participants expressed concern on how they could explain their infection to others since they had never been sexually active and did not want people to think it was their fault that they were infected. The lack of knowledge within the general population caused discrimination, and therefore to protect themselves against the discrimination, they were not going to disclose.

4.3.2.3 Keeping the secret

This sub-theme emerged when participants were asked if they had disclosed their status to anyone. Owing to the stigmatisation associated with HIV, the participants knew that they could not tell anyone outside their family that they were living with HIV. Nine of the participants decided on their own that they would not tell anyone about their status while one was told by a parent to keep the status a secret. The participants expressed that they feared being gossiped about by people if they happened to tell them. Therefore, they resorted to keeping their status a secret:

“My mother said it’s a secret between me and her and other people may then discriminate me when they know. If I don’t tell them, they won’t know that I have HIV.” (Bheki)

“I decided from that day that I would not tell anyone be it a friend or cousin, it is going to be my secret.” (Zile)

“At the clinic they told me that I don’t have to tell anyone about HIV if I don’t want to because it is my problem”.(Dudu)

The above findings resonate with a study by Madiba and Mokgatle (2016:6) who found that adolescents reported that they consider an HIV diagnosis to be secret and felt no

need to share it with anyone besides close family members. They also expressed that they do not commonly talk about HIV as a topic with their friends.

One adolescent admitted to being in a sexual romantic relationship but kept her status secret from her partner because she was worried that he would leave her if he found out. She stated that she insisted that they use protection always even though there was an instance when they did not use it.

“My boyfriend doesn’t know that I have HIV. When he asked me about my status, it was difficult to tell him so I said I was Okay. My worry is that I must come to the clinic and he may hear that I come here and eventually know that I have HIV. He has a short temper and I know that he would leave me.” (Lusanda)

A study conducted by Obare, Van der Kwaak and Birungi (2010:10) in Kenya reveals that in SSA, programmes for adolescents have not provided practical solutions for those adolescents who are sexually active or those who plan to be sexually active besides emphasising that they postpone sexual intercourse. These programmatic gaps can be attributed to HIV services focusing on the adult population with regards to Sexual Reproductive Health issues as well as socio-cultural challenges associated with addressing adolescent sexuality. Hodgson et al (2012:1) further state that ALHIV need access to Sexual Reproductive Health knowledge, services and skills to translate Sexual Reproductive Health knowledge into healthy behaviours and skills that will enable them to disclose to sexual partners.

The findings for this study are in contrast with other studies (Obare et al 2010, Midtbo et al 2012) whereby adolescents disclosed their status to their teachers so that they could assist them when they were bullied at school or when they missed lessons because they had to go to the clinic. All the adolescents in this study stated that none of their teachers knew their status because they just felt it was not necessary to tell them.

Another adolescent acknowledged being in a relationship that was not sexual. She had not disclosed at the time of the interview but was planning to tell the partner the next time she saw him. She felt it was the right time to tell him and she was not afraid of telling him because she also knew his status and that he was also living with HIV.

4.3.2.4 Disclosure setting

The participants had their status disclosed to them in different settings. Five of the participants stated that their caregivers in the home environment disclosed their status and the other five participants had their status disclosed at the clinic or hospital. The adolescents had differing views on which setting was the best to disclose the status to them. Others felt home was the best place to disclose while others preferred being told by HCP's.

"I would have wished to be told of my status at the clinic or hospital because at home if they find that you have mistakes; they then talk harshly and ask how can you be doing this when you know you have this illness." (Lusanda)

"I liked the fact that I was told by mother because she answered my questions well when I asked for clarification." (Joseph)

"The clinic is the best place to be told of your status because that is where you are tested." (Themba)

"It is better to be told by your parent at home because you feel free to ask questions and they will comfort you." (Dudu)

The findings from this study contrast with a study conducted by Mutumba et al (2015) who stated that most disclosure occurred in the healthcare environment. According to Madiba and Mokgatle (2015:7), Mumburi et al (2014:3), current recommendations are that primary caregivers should take a leading role in disclosure with HCP's providing additional information and ongoing counselling and support. Furthermore, Lorenz et al (2016:16) have a differing view in that currently there are no specific guidelines on who should disclose the diagnosis between caregiver or HCP. What is of importance is that the designated individual should consider the well-being of the child after disclosure.

However, adolescents in Zimbabwe stated clearly that they preferred disclosure in a healthcare setting. This is because the clinical space and the healthcare worker reinforced the reality of the illness, and the healthcare worker helped to clarify facts using accurate information to answer questions that may arise soon after disclosure (Kidia et al 2014:4).

4.3.3 Theme 3: Coping with HIV

The *Oxford Advanced Learner's Dictionary* (2010:324) defines coping as the ability to deal successfully with difficult situations. This sub-theme emerged when participants stated that after status disclosure, it took them time to accept that HIV was part of their lives and would influence their future decisions and plans. They reported that the acceptance of their HIV status was a gradual process that was characterised by episodes of regression. Sub-themes that emerged under this theme include family support, teen club membership and taking ART.

4.3.3.1 Support from family

All the adolescents reported that their families played a pivotal role in supporting them. The support was felt soon after disclosure as the caregivers were there to encourage them to move forward with life. The participants also reported that they still felt the support even now as the family reminded them when it was time to take medication, made sure that they kept appointments and gave them transport fare to get to the clinic for appointments.

"I feel free because everyone in my family supports me. They remind me to take my medication and encourage me to focus on schoolwork." (Neli)

"Both my parents are on ART; so, they always advise me on what to do to stay healthy." (Zile)

"My mother tries to provide for my needs; so, I am comfortable most of the time; I don't worry about anything." (Dudu)

The findings from the study concur with other studies conducted in SSA by (Hodgson et al 2012:3; Jaspán et al 2009:10; Midtbo et al 2012:267). The study found that caregivers were the first point of contact for guidance and could be beneficial and supportive after status disclosure and that adolescents need social, emotional, spiritual, and material support. A study conducted by Mburu et al (2014:6) also state that adolescents from Zambia voiced that support from immediate and extended family

members was vital as they reminded them to take their medications, cared for them when they were ill, paid their school fees, and provided them with food and clothes.

4.3.3.2 Teen club membership

This sub-theme emerged when the researcher asked participants how they coped with living with HIV. All 10 participants are part of a support club for ALHIV. The support club is aimed at helping them cope with their HIV diagnosis and to provide on-going psychosocial support while also encouraging them to adhere to treatment. The support group at the first public clinic meets on the first Saturday of the month and first Monday afternoon of the month at the second public clinic where they get an educational talk about medication adherence, nutrition, importance of abstinence, play games, and then refill their medication. All the participants expressed that the support group helped them because they felt free around each other since they had the same problem and there was no fear of discrimination. Instead, they encouraged each other to stay on treatment and aim to achieve their life goals.

“There is no worry because I take things like I am not different from other children. I don’t have those feelings of being different anymore because they teach us at the teen club about HIV and how it is treated.” (Neli)

“Now I feel free because some of my friends that I used to go to school with are also on treatment. I see them at the support group. Even when I feel scared, being with them gives me courage, so most of the time I feel free now”. (Joseph)

“I feel free because my peers here in the support group are also on treatment.”
(Zile)

Hodgson et al (2012:6) assert that ALHIV should be encouraged to join local support groups and they should be approached as young adults by recognising their evolving maturity and need for information about transitioning to adulthood. The need for effective local services becomes more imperative if the family structure is disrupted. According to Midtbo et al (2012:265), support groups helped adolescents reduce stress when they had problems at home, and for some, it was the only place where they had friends. They also gained knowledge about HIV, medication, stigma, reproductive health, how to avoid re-infection while also protecting others from HIV, including

knowledge on how to respect others. The teen club was described as a place where the adolescents could be open with each other and their status without fear.

4.3.3.3 Taking ART

ART refers to triple or more retroviral drug combination to maximally suppress the HIV virus and stop progression of HIV disease (UNAIDS 2011:7). The sub-theme came about because participants stated that taking ART helped them to lead healthier lives. All the participants are on ART and most adolescents stated that they have accepted taking ART for the rest of their lives to ensure good health. They understood that for them to stay healthy they had to strictly take to their medication. Their wish was to lead normal lives like other children of their age and looking forward to achieving their dreams and ambitions. Taking treatment gave them a sense of being in control of their lives and decreased the fear of death owing to HIV that they had when their status was initially disclosed. None of the participants experienced side effects from the treatment and they took it once a day in the evening. They also articulated that they did not usually visit away from their homes and this minimised moments where they felt they could not take their medications freely.

“I take my pills correctly because ever since I started taking them I haven’t been sick at all. I feel fine. I know that if I skip them I will get sick again and I don’t want that.” (Sindi)

“At first, I thought will I be able to take medication daily because I can’t even finish medication for minor illnesses? Once I started the medication, I discovered that it didn’t affect me in anyway. I know I will live for a long time.” (Zile)

“The ARV’s have brought good change to my life. I don’t have to worry about getting sick anymore if I take them right.” (Gugu).

The above findings are supported by studies conducted by Jaspan et al (2009:10) in South Africa, and Midtbo et al (2012:265) in Botswana and Tanzania. These studies reveal that adherence to treatment is essential for sustaining positive health outcomes. Therefore, young people living with HIV need support in maintaining their treatment and that the availability of ART contributes to a feeling of safety for the adolescents since there is belief that ART enabled one to live a long healthy life.

4.4 CONCLUSION

This chapter discussed the results and interpretation of data analysis using literature review as a reference. Demographic information of the participants was presented first to give a background followed by themes which emerged during the analysis. The first theme, that is, living with HIV infection had three sub-themes, namely, fear of death, recurrent sickness and loss of parents. The second theme disclosure of HIV status had four sub-themes, namely, knowing own HIV status, self - disclosure, keeping the secret and disclosure setting. The third theme coping with HIV had three sub-themes, namely, family support, teen club membership and taking ART. The following chapter will discuss the conclusion, contributions, limitations of the study and future recommendations will be presented.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The previous chapter presented and discussed findings of the study. Three themes emerged during data analysis, namely, living with HIV infection, disclosure of HIV status and coping with HIV. In this last chapter of the dissertation, the researcher will present conclusions and recommendations applicable to the study. In addition, the chapter will summarise the research design and methodology utilised in the study, interpretation of research findings, recommendations, limitations, and contributions of the study. The study was conducted in two clinics in the Hhohho Region of Swaziland. The purpose of the study was to understand the experiences of adolescents' (15-19 years) after the disclosure of their HIV status disclosure and the research question which was explored was, *"What are the experiences of adolescents about the disclosure of their HIV status disclosure to them?"* The researcher further used probes to get clarification from participants.

The objectives of the study were as follows:

- To explore and describe adolescents' experiences after their HIV status was disclosed to them.
- To make recommendations based on the findings of the study on a suitable procedure to disclose to adolescents their HIV status.

5.2 RESEARCH DESIGN AND METHODOLOGY

The study used a qualitative, explorative and descriptive design to understand the experiences of the adolescents after their HIV status was disclosed to them. The researcher opted for the qualitative approach because it seeks to explore and describe how individuals interpret and make sense of their personal experiences. The sample in this study was 10 ALHIV (six females and four males), who were aged 15 -19 years and

were receiving ART. These are the participants who volunteered to participate in the study because they were open about their status and did not find talking about their status stressful. Purposive sampling, which is a non-probability sampling technique, was used whereby the researcher selected participants based on personal judgement.

The researcher collected data through in-depth individual semi-structured face-to-face interviews, which were recorded using a voice recorder. Participants consented first before interviews commenced. During the interviews, the researcher observed non-verbal cues and also took field notes. The objectives of the study were answered because the adolescents could share their experiences of HIV status disclosure and provided the researcher with insight on what recommendations would be most useful based on the responses they gave. The researcher also realised that this age group needs to be treated carefully as they are not yet sure if they are still children or adults. The researcher will also be able to articulate what support measures are needed by ALHIV after status disclosure. The recommendations will be discussed under heading 5.4

5.3 SUMMARY AND INTERPRETATION OF RESEARCH FINDINGS

After data collection, the researcher typed the field notes of all the interviews. The data were transcribed verbatim and later translated to English. Translated data was sent to the Siswati speaker to check that captured information had not lost meaning. Data analysis was done utilising Tesch's qualitative data analysis approach. Transcripts were read until the researcher became familiar with the data. The next step was identifying specific topics in the interviews. Similar topics were clustered together according to similarity and turned into categories. The categories were reduced by grouping topics that relate to each other together with the themes. The researcher constructed an organising system whereby existing data was coded and organised into three broad themes, namely, living with HIV infection, disclosure of HIV status and coping with HIV. A preliminary analysis was done and irrelevant information was eliminated.

5.3.1 Living with HIV infection

All the participants in the study described living with HIV as a painful experience that brought distress in their young lives. The participants felt anger, shock, disbelief, and

fear after HIV status disclosure. All the participants had experienced previous episodes of poor health, which resulted in them missing school leading to them repeating grades because they could not catch up at school after episodes of illness. Participants were also worried about early death related to HIV, especially after the death of their biological parents. In a study conducted in Swaziland, Shabalala, De Lannoy, Moyer and Reis (2016:13) allude that adolescents found it difficult to accept living with HIV because they believed they would eventually die from AIDS despite taking pills every day for the rest of their lives. Most participants experienced physical developmental delays in that they were short and small for their age and could be mistaken to be younger than they were. Some of the adolescents were living in homes not headed by their parents, and some had to change residences after parental loss.

5.3.2 Disclosure of HIV status

The earliest age of disclosure for the adolescents was seven years while the latest age of disclosure was 15 years. Disclosure was treated as an event rather than a process and was necessitated by the participants being sick and needing hospitalisation. Gyamfi, Okyere, Enoch and Appiah-Brempong (2017:1) argue that one of the greatest challenges of parents and caregivers of children living with HIV are disclosure to their children despite that it has numerous benefits. Gyamfi et al (2017:1) further assert that the WHO recommends that as part of their long-term management, school-going children should have their HIV status disclosed to them and those who are still young be told incrementally to accommodate their limited cognitive skills and emotional maturity thereby preparing them for full disclosure at a later stage.

The participants reported feelings of anger, disorientation, sadness, and the urge to stop the medication after disclosure and finally acceptance. Gachanja (2015:5) reached the same conclusion whereby Kenyan children expressed shock after disclosure but were happy that they knew their status. However, they first experienced negative emotions like anger and blame towards their parents for infecting them with the disease before they finally accepted their circumstances and returned to their normal state. The participants stated that parents told them that they should keep their HIV status secret from others outside the family while others decided for themselves that they were going to tell no one because they feared discrimination and stigmatisation. The participants who had partners stated that they had not disclosed to them because they worried how

they would handle the news. Some of the participants preferred to have their HIV status disclosed to them in a healthcare setting while others preferred that disclosure is done at home in their familiar surroundings.

5.3.3 Coping with HIV

Participants reported that the acceptance of their HIV status was a gradual process. They reported that their families played a crucial role in helping them cope with the HIV diagnosis. Moreover, the families supported the adolescents by encouraging them to take medication, making sure that they kept appointments and gave them transport fare for clinic appointments. Coping is assessed by how well an individual behaviourally and cognitively addresses the stress they are going through (Gachanja 2015:3 citing Lazarus 1993). Gachanja (2015:5) further reiterates that an individual's problem-focused coping is enhanced by adaptation to their environment while emotion-focused coping is improved by anticipating which situations lead to stress and then avoiding the identified stresses.

Counselling services were also highlighted as crucial for adolescents as they felt free to ask questions regarding their health, HIV and general life issues, therefore enabling them to improve their health through knowledge (Midtbo et al 2012:265). Participants were part of teen support groups which met once a month. The support groups were considered a safe place for them to be in and they felt that it is where they could talk about anything without fear of being judged because they all attended the support group with one purpose. The support group helped the adolescents by educating them on treatment adherence, issues of sexuality, and having a positive outlook towards life. Midtbo et al (2012:265) further assert that support groups engage adolescents in various activities that help to alleviate stress and encourage them how to live healthily with ART. All the participants were on ART and they reported that they have accepted taking treatment for the rest of their lives to ensure good health.

5.4 RECOMMENDATIONS

5.4.1 Recommendations for clinical practice

The following are recommendations with regards to the clinical nursing practice aimed at empowering the clinical nurses regarding disclosure of HIV status to adolescents:

- HCP's should form support groups for adolescents living with HIV to help adolescents cope better with HIV infection and other issues that come with living with a chronic condition.
- It is important for the HCPs to understand how adolescents think and what their expectations are.
- HCP's must make sure that the de-stigmatisation of the HIV is the most important aspect of care in health care facilities.
- It is also important to make sure that the health care facilities are youth/adolescent user-friendly and these adolescents are not ridiculed at the health care centres.
- HCP's should form support groups for adolescents living with HIV to help adolescents cope better with HIV infection and other issues that come with living with a chronic condition.
- Caregivers should be educated about the importance of HIV disclosure to their children as early as they (children) could understand the condition.
- Caregivers of children with HIV to have their own support group as this will help them cope better with the condition.

5.4.2 Recommendations for nursing education

The recommendations with regards to nursing education, based on the findings from this study are as follows:

- There should be revision of the curriculum and integration of adolescence HIV infection management with particular attention on how to handle disclosure efficiently.

- Capacitating nursing students with up-to-date knowledge and skills on how to effectively provide service to adolescents living with HIV before they join the workforce.
- Curriculum has to address the current issues, which include the adolescents as the vulnerable group handling.
- Student nurses to be well informed about the ethics and professional secrecy and be able to advocate for the adolescents.

5.4.3 Recommendations for future research

Based on the findings of this research, the future research can be based on the following recommendations:

- More clinics in the Hhohho Region should be included in future studies as well as other regions in Swaziland to cover a wide geographical area.
- Conduct a quantitative study using a bigger sample, which would make it easier to generalise findings with the assurance that it is representative of adolescents living with HIV in Swaziland.
- Future studies in this topic should include HCP's and caregivers to share their views as they are the ones primarily responsible for disclosure to the adolescents.
- Their involvement in future studies would unearth vital information and give an all-inclusive view that would give a clear direction on which area should be focused on to disclose to adolescents in a way that would help them accept their status and integrate HIV into their lives without too much stress.
- The use of other methods like mixed methods which will assist in the more in-depth understanding of the phenomena under investigation.
- More research is also needed to address the de-stigmatisation of the HIV status, especially among the adolescents.

5.5 CONTRIBUTIONS OF THE STUDY

The study has invaluable contributions regardless of its limitations that could assist the Ministry of Health, HPC's and caregivers and other relevant stakeholders through:

- Understanding how the adolescents feel about their status disclosure in order to take necessary precautions when dealing with them.
- Acknowledging that adolescents are a vulnerable group; therefore; it is important not to withhold information about their status from them as they are very sexually active and could put their sexual partners at risk of acquiring HIV infection if their HIV status was never disclosed to them.
- Adolescent ART centres should be made available for the exclusive use by ALHIV as they would help adolescents feel free to attend them without fear of stigmatisation.
- Promulgation of the policies by the Department of Health that will specifically address the issues that are dealing with the adolescents.

5.6 LIMITATIONS OF THE STUDY

There were limitations of this study and were identified and managed as follows:

- The study was based on perceptions of the ALHIV that were part of the study and it was only confined to two clinics in the Hhohho Region. The choice of the research setting was because the participants were a vulnerable group.
- The findings cannot be generalised to a wider population of all ALHIV in Swaziland since they are applicable to the adolescents that were selected for the study only. Therefore, the views expressed here are only for those adolescents that participated in the study.
- If the same study could be repeated, it could reveal different experiences as each individual has their own way of interpreting the same situation.
- The adolescents who were part of the study were living in peri-urban communities instead of also being inclusive of rural communities as the inclusion of adolescents from different backgrounds could bring out varied and more valuable responses.

5.7 CONCLUDING REMARKS

The study explored the experiences of ALHIV after status disclosure in two clinics in the Hhohho Region of Swaziland. The study unearthed challenges that adolescents faced

regarding HIV status disclosure since the HIV status was not disclosed to them soon after they were diagnosed with HIV infection. Furthermore, disclosure was treated as a once off event rather than as a process. It is essential that appropriate interventions are executed by involving various stakeholders in order to enhance the self-esteem of the adolescents living with HIV, minimise stigma and discrimination while also capacitating them with self-disclosure skills.

5.8 CONCLUSION

The study was conducted in the Hhohho Region of Swaziland and the purpose of the study was to understand the experiences of adolescents' (15-19 years) after their HIV status disclosure. The objectives of the study were met by utilising the qualitative, explorative and descriptive design. Data were collected by the researcher through in-depth individual semi-structured face-to-face interviews from 10 participants. In addition, data were analysed after which three themes emerged, namely, living with HIV infection, disclosure of HIV status and coping with HIV.

The research made the following recommendations:

- HCP's should form support groups for adolescents living with HIV to help adolescents cope better with HIV infection.
- There should be revision of the curriculum and integration of adolescence HIV infection management on how to handle disclosure efficiently to capacitating nursing students with up-to-date knowledge.
- That adolescent ART centres should be made available for the exclusive use by ALHIV as they would help adolescents feel free to attend them without fear of stigmatisation.

The study also had limitations because the study was confined to two clinics in the Hhohho Region. Therefore, the findings cannot be generalised to a wider population of all ALHIV in Swaziland. The adolescents who were part of the study were living in peri-urban communities instead of also being inclusive of rural communities.

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ANNEXURES

ANNEXURE A

Letter of application to conduct a study

PO Box 4238

Mbabane

H 100

14 July 2017

The Sister in Charge

Mahwalala clinic

Mbabane

Swaziland

Dear Madam

RE: APPLICATION FOR PERMISSION TO CONDUCT A STUDY

I Baliwe Philile Dlamini, a registered nurse and a Master's degree student at the University of South Africa (UNISA) hereby kindly request the authorities of Mahwalala clinic to grant me permission to conduct a research study at your facility. In partial fulfilment of my Master's degree I am expected to conduct research. The title of the study is "Experiences of adolescents upon knowing their HIV status in Hhohho region: Swaziland."

I would like to have participants (male and female) living with HIV and are already on Anti-Retroviral Therapy. Data will be collected through individual face to face semi-structured interviews using the home language Siswati. In order to participate in this study the adolescent must be aware of the HIV status, be willing to participate in the study, and must sign an assent form. Caregivers will be asked to sign their own consent forms.

The selected adolescents will be given dates on which they can avail themselves for interviews. If any participant feels they would like to withdraw from the study at any point

they will be allowed to. The researcher will keep participants' identities confidential throughout the research study.

I would greatly appreciate if I can be granted permission to undertake this study. For further information or clarification please contact me at:

Mobile phone: 7602 1304

Email address: baliwep@gmail.com

Yours sincerely

.....

Baliwe Philile Dlamini

P O Box 4238
Mbabane
H 100
14th July 2017

The Sister in Charge
Ezulwini clinic
Mbabane
Swaziland

Dear Madam

RE: APPLICATION FOR PERMISSION TO CONDUCT A STUDY

I Baliwe Philile Dlamini, a registered nurse and a Master's degree student at the University of South Africa (UNISA) hereby kindly request the management of Ezulwini clinic to grant me permission to conduct a research study at your facility. In partial fulfilment of my Master's degree I am expected to conduct research. The title of the study is "Experiences of adolescents upon knowing their HIV status in Hhohho region: Swaziland."

I would like to have participants (male and female) living with HIV and are already on Anti-Retroviral Therapy. Data will be collected through individual face to face semi structured interviews using the home language Siswati. In order to participate in this study the adolescent must be aware of the HIV status, be willing to participate in the study, and must sign an assent form. Caregivers will be asked to sign their own consent forms.

The selected adolescents will be given dates on which they can avail themselves for interviews. If any participant feels they would like to withdraw from the study at any point they will be allowed to. The researcher will keep participants' identities confidential throughout the research study.

I would greatly appreciate if I can be granted permission to undertake this study. For further information or clarification please contact me at:

Mobile phone: 7602 1304

Email address: baliwep@gmail.com

Yours sincerely

.....

Baliwe Philile Dlamini

ANNEXURE B:

Information and consent form for caregiver

Title of study: Experiences of adolescents upon knowing their HIV status in the Hhohho Region: Swaziland

My name is Baliwe Philile Dlamini, a registered nurse and a Master's degree student at the University of South Africa (UNISA). I am requesting permission for your child to take part in a research study. Before you agree for your child to take part in this study please go through this letter as it will help clarify a few things you might want to know. My contact details are 7602 1304 (mobile phone).

PURPOSE OF THE INTERVIEW

The purpose of the interview is to explore the experiences of adolescents upon knowing their HIV status.

RESEARCH PROCESS

1. The individual interview will be led by the researcher and will last for approximately 40 minutes.
2. It will be conducted in a room that will be allocated for this purpose. The researcher will make all means possible to ensure that your child does not experience any foreseeable discomfort, but be relaxed and at ease at all times.
3. There is no right or wrong answer and all opinions will be respected and valued.
4. There is no preparation needed in advance for the interview.
5. A social worker will be on standby to attend to your child if they experience episodes of emotional upset.

NOTIFICATION THAT THE INTERVIEW WILL BE TAPE RECORDED

Your attention is drawn to the fact that the interview will be tape recorded to ensure that the valuable information provided during the interview is captured and the context of the information can be reviewed in detail. Following the interview, the recorded material will be transcribed.

CONFIDENTIALITY

The opinions expressed by your child will be viewed as strictly confidential, and only the researcher will have access to the information. No data published as a result of this study will contain any information through which your child may be identified. Anonymity is therefore guaranteed.

WITHDRAWAL FROM THE STUDY

Your child is free to withdraw from the interview at any time for any reason. It is his/her right to do so and it will be respected.

INFORMATION

If you may have any questions concerning the study, you are welcome to contact my supervisor, Dr D.D Mphuthi, Department of Health Studies University of South Africa at e-mail mphutdd@unisa.ac.za .

CAREGIVER CONSENT

I have read the above information relating to the research, and declare that I understand this information. I have been given the opportunity to discuss relevant aspects of the research with the researcher, and hereby declare that I agree voluntarily for my child to participate in the research.

Signature of caregiver:

Signature of researcher:

Signed at on

ANNEXURE C:

Adolescent information sheet and assent form

My name is Baliwe Philie Dlamini. I am a registered nurse and a Master's student at the University of South Africa (UNISA) who is conducting a study on the experiences of adolescents upon knowing their HIV status. I would like to talk to you about experiences you had after your HIV status was disclosed to you.

If you agree to participate in the research study, I will conduct an individual interview that will last for approximately 40 minutes. Whatever we will be talking about during the interview will be confidential and your name will not appear in any document.

During the interview, I will be using a tape recorder that will record all our conversation. This is to assist me in remembering what we talked about during the interview. This tape recorder will be kept safe and I am the only one who will have access to it.

Owing to the nature of the research, some questions may be uncomfortable and if that happens during the course of the interview please let the researcher know. I have also asked for permission from your caregiver to interview you and consent was given. If at any time after consent you feel you do not want to participate you will not be forced to continue.

If you have any questions or you need clarification on any issue pertaining this request please feel free to contact me on this number 7602 1304. There is no payment attached to participating in this study but you will be given E50 to cover transport costs on the day of the interview.

ADOLESCENT ASSENT

I agree to take part in this study and fully understand my rights in relation to participation.

Signature of the child

Signature of researcher

Signed at on

ANNEXURE D

Interview guide

- Please tell me briefly about yourself (how old you are, your type of family, which school you attend).
- What is your experience of HIV status disclosure?
- Can you tell me how you got to know your HIV status (when, where and who told you)?
- How did you feel immediately after learning about your HIV status?
- As an individual how does living with HIV make you feel?
- Have you been able to confide in others about your status e.g friends or significant others?
- How did you feel after disclosing your status to your friends or significant others?
- After disclosure how did the people you were disclosing to react towards you?
- If you have not disclosed, what is holding you back from disclosing your status?
- How do you cope with your HIV status/living with HIV?
- If things were to be done differently how do you think your HIV status should have been disclosed to you?
- Was your HIV status disclosed once or it was disclosed in stages?
- Are there any questions that you have for me?

Thank you for your time

ANNEXURE E

Unisa ethical clearance letter



RESEARCH ETHICS COMMITTEE: DEPARTMENT OF HEALTH STUDIES
REC-012714-039 (NHERC)

7 December 2016

Dear Mrs BP Dlamini

Decision: Ethics Approval

HSHDC/568/2016

Mrs BP Dlamini

Student: 3506-245-2

Supervisor: Dr DD Mphuthi

Qualification: PhD

Joint Supervisor: -

Name: Mrs BP Dlamini

Proposal: Experiences of adolescents upon knowing their HIV status in Hhohho region: Swaziland.

Qualification: MPCHS94

Thank you for the application for research ethics approval from the Research Ethics Committee: Department of Health Studies, for the above mentioned research. Final approval is granted for the duration of the research period as indicated in your application.

The application was reviewed in compliance with the Unisa Policy on Research Ethics by the Research Ethics Committee: Department of Health Studies on 7 December 2016.

The proposed research may now commence with the proviso that:

- 1) The researcher/s will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.*
- 2) Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study, as well as changes in the methodology, should be communicated in writing to the Research Ethics Review Committee, Department of Health Studies. An amended application could be requested if there are substantial changes from the existing proposal, especially if those changes affect any of the study-related risks for the research participants.*



University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

3) *The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study.*

4) *[Stipulate any reporting requirements if applicable].*

Note:

The reference numbers [top middle and right corner of this communiqué] should be clearly indicated on all forms of communication [e.g. Webmail, E-mail messages, letters] with the intended research participants, as well as with the Research Ethics Committee: Department of Health Studies.

Kind regards,



Prof L Roets

CHAIRPERSON

roetsl@unisa.ac.za



Prof MM Moleki

ACADEMIC CHAIRPERSON

molekmm@unisa.ac.za

Approval template 2014

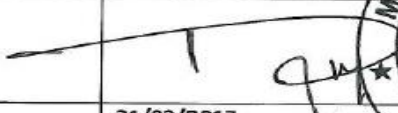
University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

ANNEXURE F

National Research Review Board clearance



Research Protocol clearance certificate

Type of review	Expedited	<input checked="" type="checkbox"/>		Full Board	<input type="checkbox"/>	
Name of Organization	STUDENT					
Title of study	THE EXPERIENCES OF HIV STATUS DISCLOSURE TO ADOLESCENTS IN HHOHHO REGION, SWAZILAND.					
Protocol version	1.0					
Nature of protocol	New	<input checked="" type="checkbox"/>		Amendment	<input type="checkbox"/>	
List of study sites	BAYLOR CLINIC					
Name of Principal Investigator	BALIWE DLAMINI					
Names of Co- Investigators	N/A					
Names of steering committee members in the case of clinical trials	N/A					
Names of Data and Safety Committee members in the case of clinical trials	N/A					
Level of risk (Tick appropriate box)	Minimal	<input checked="" type="checkbox"/>		High	<input type="checkbox"/>	
Clearance status (Tick appropriate box)	Approved	<input checked="" type="checkbox"/>		Disapproved	<input type="checkbox"/>	
Clearance validity period	Start date	21/03/2017			End date	21/03/2018
Signature of Chairperson						
Date of signing	21/03/2017					
Secretariat Contact Details	Name of contact officers	M. Masilela				
	Email address	kaluamasi@gmail.com				
	Telephone no.	(00268) 24040865/24044905				



Approval Conditions

Ref.	Conditions	Indication of conditions (tick appropriate box)				
1	Implementation of approved version of protocol	✓				
2	Reporting of adverse events within 5 days of occurrence	✓				
3	Submission of progress reporting for multi-year studies	Yr 1 N/A	Yr 2 N/A	Yr 3 N/A	Yr 4 N/A	Yr 5 N/A
4	Submission of end of project report (Hard copy)	✓				
5	Submission of end of project report (Soft copy)	✓				
6	Submission of data sets	✓				

List of reviewed documents

Ref.	Documents	Reviewed documents (tick appropriate box)
1	Completed application form	✓
2	Cover letter	✓
3	Evidence of administrative permission to conduct the research by involved institutions/sites (where applicable)	✓
4	Detailed current resume or curriculum vitae of Principal Investigator/s including Principal investigators declaration	✓
5	Summary resume or biography for other investigator(s)	✓
6	Evidence of approval/rejection by other Ethics Committees, including comments and requested alterations to the protocol, where appropriate.	
7	Research protocol (see outline in Annex 1)	✓
8	Questionnaires and interview guides (with back-translated versions where applicable)	✓
9	Case report forms (CRFs), abstraction forms and other data collection tools	✓
10	Participant/subjects Information Statement(s) (where applicable)	✓
11	Informed consent form(s) including photographic and electronic media consent statements.	✓
12	Advertisements relevant to the study (where applicable)	
13	Source of funding and detailed budget breakdown including material and incentives to participants if applicable	
14	Notification form for adverse effects/events.	
15	Proof of payment	✓
16	Proof of insurance cover for research subjects in clinical trials or where applicable	
17	Any other special requirements should be stated, if applicable	None



ANNEXURE G

Permission to conduct study

<p>Ministry of Health</p>  <p>Nobuhle Mthethwa SNAP National Pediatric HIV Care & Treatment Advisor</p> <p>Tel: +268 2404 9474 Email: bubu.mthethwa@gmail.com Cell: +268 7618 7951 nmthethwa@pedaids.org</p> <p>Fax: (+208 404 2092</p>		<p>MINISTRY OF HEALTH P.O. BOX 5 MBABANE SWAZILAND</p>
<p>THE KINGDOM OF SWAZILAND</p>		
<p>30th May 2017</p>		
<p>The Sister in Charge</p>		
<p>Dear Sir/Madam</p>		
<p><u>RE: PERMISSION TO CONDUCT A MAIN STUDY</u></p>		
<p>Please allow BALIWE P DLAMINI – a Bachelor of Nursing Science Degree student at the University of South Africa (UNISA) to conduct a main study in June, 2017 at your Clinic.</p>		
<p>The title of the study is EXPERIENCE OF ADOLESCENTS UPON KNOWING THEIR HIV STATUS IN THE HHOHHO REGION. The study is in partial fulfilment of the requirements for the Bachelor of Nursing Science Degree.</p>		
<p>Anonymity will be maintained throughout the study. Thanking you in advance for your favourable consideration.</p>		
<p>Yours Faithfully</p> <div style="display: flex; align-items: center;"><div style="margin-right: 20px;"><p>MUHLE DLAMINI SNAP Manager Ministry Of Health</p></div><div style="border: 2px solid blue; border-radius: 50%; padding: 10px; text-align: center;"><p>GOVERNMENT OF SWAZILAND NATIONAL AIDS PROGRAMME 05 JUN 2017 P O BOX 1119 MBABANE TEL. 404 5397 MINISTRY OF HEALTH</p></div></div>		

BAPHALALI SWAZILAND RED CROSS SOCIETY

Mbabane Division / Mahwalala clinic



Patron: His Majesty King Mswati III

Baliwe P. Dlamini
P.O. Box 4238
Mbabane
H100

Permission to Conduct a Research Study

Title of the study- Experience of Adolescents upon knowing their HIV status in the Hhohho Region.

It is our pleasure to grant you permission to conduct this study in our facility

Yours Sincerely,



Zondi Puleng
Mahwalala Clinic-Head Nurse



Postal Address
P.O. Box 3488
Mbabane

Telephone: 47-28282/55-10686
Cable: "Baphalali"
Swaziland

ANNEXURE H:

Language editing certificate

EDITING AND PROOFREADING CERTIFICATE

7542 Galangal Street

Lotus Gardens

Pretoria

0008

31 October 2017

TO WHOM IT MAY CONCERN

This letter serves to confirm that I have edited and proofread Ms BP Dlamini's dissertation entitled: **"THE EXPERIENCE OF HIV STATUS DISCLOSURE TO ADOLESCENTS IN HHOHHO REGION: SWAZILAND"**.

I found the work easy and intriguing to read. Much of my editing basically dealt with obstructionist technical aspects of language which could have otherwise compromised smooth reading as well as the sense of the information being conveyed. I hope that the work will be found to be of an acceptable standard. I am a member of Professional Editors Guild.

Hereunder are my particulars:



Jack Chokwe (Mr)

Contact numbers: 072 214 5489

jackchokwe@gmail.com

Professional
EDITORS
Guild

ANNEXURE I

Transcribed interviews

Interview 1 with Neli English version

Researcher: The researcher first tried to put the participant at ease by holding eye contact and smiling, then passed greetings..... “Good morning, as I have already introduced myself please tell me briefly about yourself (how old you are, which school you attend, your type of family)”.

Neli: Smiles looks relaxed..... “I am 17 years old and I go to MDS High school. Pause.... I am doing grade 10. I stay with both my grandparents and uncle, both my parents are teachers so most of the time I don’t stay with them but they come to check on me”.

Researcher: “Do you stay near here?”.

Neli: “I stay in Nkwalini zone 3. My mother is a teacher at St Marys Primary and I don’t know where my father teaches but he teaches in the country, I just don’t know where exactly”.

Researcher: “Are you an only child or do you have siblings?”

Neli: Moment of quietness..... “My brother is the first born, followed by me then there is the last born”.

Researcher: “How old is your brother?”

Neli: Tries to recall..... “He is 26 years old”.

Researcher: “And how old is the one who comes after you?”

Neli: “She is nine years old”.

Researcher: “You said you stay with your grandparents, where do your siblings stay?”

Neli: “My brother stays in Manzini because he is doing laboratory studies and my sister stays with my mother at school”.

Researcher: “Where you stay now whose home is it?”

Neli: period of silence..... “It is my mother’s homestead”.

Researcher: “What is your experience of HIV status disclosure?”

Neli: Sighs and looks pensive.... “After I was told of my status I thought I was going to die because I knew that if you have HIV you die and I asked myself many questions like why me, why am I not negative like my brother or sister. I also felt extremely sad”.

Researcher: The researcher posed a probing question... “How did you express your sadness?”

Neli: “I kept the pain inside me. When I am sad I just need to be alone and quiet and after some time I feel better”.

Researcher: “Can you tell me how you got to know your HIV status (when, where and who told you)?”

Neli: “I knew my status when I was nine years old. My mother told me that it was discovered after I was born that I have HIV”.

Researcher: “Do you remember which year it was?”

Neli: Mhh.... “I don’t remember”.

Researcher: “Where were you when she told you? At home or the clinic and how did the conversation start?”

Neli: Looks down.... “She told me at home when it was just the two of us. After that I had questions when? How? And even doubted myself... I also wondered how I was going to live from then on”.

Researcher: “Did you ask before your mother told you about your status or she just felt that you were ready to know?”

Neli: “She just told me without me asking anything”.

Researcher: “Were you already taking medication at that time?”

Neli: “Yes I was but I hadn’t taken notice that I was drinking medication everyday”.

Researcher: “How did you feel immediately after learning about your HIV status?”

Neli: Frowns.... period of quietness... “I got angry and I was asking myself why my mother was telling me this now”.

Researcher: Pause..... then asks “Did you feel she should have told you a long time ago or she should have waited until you were a little bit older?”

Neli: “She should have waited until I was a little bit older”.

Researcher: The researcher probes.... “Why did you feel that way?”

Neli: “I just felt that if I was older I would handle the news better”.

Researcher: “What else did you feel?”

Neli: Aah.... “I felt that I was different from other children and asked myself how I was going to live”.

Researcher: “As an individual, how does living with HIV make you feel?”

Neli: “I feel free because everyone in my family supports me. They remind me to take my medication and encourage me to focus on schoolwork”.

Researcher: “When do you take your medication? And does it give you any problems?”

Neli: “I take medicine at 7 in the evening, I chose that time because am usually at home then. The medicine does not give me problems”.

Researcher: “Do you know the HIV status of your siblings?”

Neli: “Yes, they are negative”.

Researcher: “Have you been able to confide in others about your status e.g friends or significant others?”

Neli: “No I have not told anyone”.

Researcher: “Have you been able to tell your friends?”

Neli: “No”.

Researcher: Looking intently at the participant.... “What makes you not to be at ease to tell them about your status?”

Neli: Twists hands.... “I think that if I tell them they will treat me differently from others because I have HIV and start saying funny things”.

Researcher: The researcher further probed.....“Please clarify what you mean by funny things”.

Neli: “They will tell the story to others and then it will spread like that and embarrass me”.

Researcher: “You don’t trust even your friends to keep your status confidential?”

Neli: “No I don’t trust my friends, we talk about everything else except HIV”.

Researcher: “Do you think you could tell them at some point in time or you believe it’s your thing?”

Neli: “No, I believe it’s my thing, how would I explain to them how I got it? No matter what I say, behind my back they will be talking, saying she was sleeping around that is why she has it”.

Researcher: “How do you cope with your HIV status?”

Neli: “There is no worry because I take things like I am not different from other children, I don’t have those feelings of being different anymore because they teach us at the teen club about HIV and how it is treated. I now understand that I’m not different from a person suffering from BP or diabetes”.

Researcher: “If things were to be done differently how do you think your HIV status should have been disclosed to you?”

Neli: “I wish I could have been told of my status at the clinic”.

Researcher: The researcher probes the participant.....“Why do you prefer the clinic?”

Neli: “It was going to be easy for me to understand because they explain more clearly”.

Researcher: “Did your mother disclose all the information about HIV at once or in stages?”

Neli: “She told me at once, the other times we talked about my status was when I had asked something”.

Researcher: “Do you have any questions you would like to ask me?”

Neli: “No I don’t have questions”.

Researcher: “Thank you for your time”.

Neli: “Okay bye”.

Interview with Neli Siswati version

Researcher: Umcwaningi wacala ngekwemukela umncwaningwa kutsi atokhululeka ngekumubuka emehlweni, nekumoyitela wase uyambingelela “Sawubona, njengoba besengitetfulile mine ngicela ungitjele kafishane ngawe (kutsi unamingaki iminyaka, ufundzaphi nekutsi usuka ekhaya lelinjani)”.

Neli: Umcwaningwa amoyitele “Ngineminyaka lelishumi nesikhombisa, ngifundza e MDS High school. Wabindza sikhashana.... Ngifundza libanga lelishumi. Ngihlala nabo gogo namkhulu kanye namalume, Batali bami babothisela sikhatsi lesinyenti angihlali nabo kepha bayeta batongihlola.

Researcher: “Uhlala dvute nalapha yini?”

Neli: “Ngihlala e Nkwalini zone 3. Make ufundzisa e St Marys Primary, babe angimati ufundzisa kuphi kepha ulakaNgwane, mane sengikhohliwe kutsi kuphi nendzawo”.

Researcher: “Watalwa wedvwa yini noma unabo lotalwa nabo?”

Neli: Wacala wabindza sikhashana.... “Umnaketfu lomdzala wekucala, alandzelwe ngimi bese kuta wekugcina”.

Researcher: “Unamingaki iminyaka umnakenu?”

Neli: Azame kukhumbula.... “Unemashumi lamabili nesitfupha umnyaka”.

Researcher: “Unganani ke lona lota emuva kwakho?”

Neli: “Uneminyaka leyimfica”.

Researcher: “Utsite uhlala nabogogo namkhulu, bahlalaphi lotalwa nabo?”

Neli: “Umnaketfu uhlala ka Manzini ngoba ufundza tifundvo tabo laboratory, sisi wami uhlala namake esikolweni”.

Researcher: “Lawuhlala khona nyalo kusekhabo muphi umtali wakho?”

Neli: Acale abindze sikhashana.... “Kusekhaya kubo make”.

Researcher: “Ngifisa kuva imicabango nendlela lowativa ngayo mzu kwana watiswa ngesimo sakho sengati mayelana neligciwane le HIV njengemuntfu lomusha?”

Neli: Atsatse umoya abukeke acabanga lokujulile.... “Emuva kwekutjelwa ngesimo sami sengati ngacabanga kutsi ngitakufa ngoba bengati kutsi nawuneligciwane le HIV uyafa, ngaphindze ngatibuta kutsi leni mine, yini ngingabi negative njengabhuti noma sisi wami. Ngaphindza ngeva buhlungu kakhulu”.

Researcher: Umcwaningi abute umbuto kucaciseleka.... “Watjengisa kanjani kutsi uva buhlungu?”

Neli: “Ngabugcina langekhatsi kimi lobuhlungu. Uma ngiva buhlungu ngidzinga nje kutsi ngibe ngedvwa phindze ngithule ngingakhulumi namuntfu, emuva kwesikhatsi ngibese ngitiva ngincono”.

Researcher: “Ungangitjela yini kutsi wati kanjani ngesimo sakho sengati (nini, bewukuphi indzawo nekutsi watjelwa ngubani)?”

Neli: “Simo sami sengati ngasati nangingeminyaka leyimfica budzala. Make wangitjela kutsi kwatfolakala emuva kwekuba ngitalwe kutsi ngineligciwane le HIV”.

Researcher: “Uyawukhumbula yini umnyaka kutsi bekunguwuphi?”

Neli: Azame kucabanga.... “Hhayi angiwukhumbuli”.

Researcher: “Benikuphi indzawo nakakutjela make? Ekhaya noma emtfolamphilo, nekutsi yacala njani lenkhulumo?”

Neli: Abuke phansi.... “Wangitjela sisekhaya sisobabili. Emuva kwaloko ngatibuta imibuto nini? Njani? Ngaze ngaba nekutingabata.... Ngatibuta kutsi sengitophila njani kusukela leso sikhatsi”.

Researcher: “Bewumbutile yini make nakakutjela ngesimo sakho sengati noma wavele wakutjela ngoba bekabona kutsi sowufanele kwati?”

Neli: “Chake wavele wangitjela ngingakabuti lutfo”.

Researcher: “Besowucalile yini kunatsa emaphilisi ngaleso sikhatsi akutjela?”

Neli: “Yebo kepha bengisengakanaki kutsi nginatsa emaphilisi onkhe malanga”.

Researcher: “Wativa unjani emuva kwekuba utjelwe ngesimo sakho sengati?”

Neli: Aswace.... Athule sikhashana.... “Ngakwata ngatibuta kutsi yini make angitjele nyalo”

Researcher: Kubindze sikhashana.... “Bowuva ngatsi ngabe wakutjela kadzeni noma ngabe wakumela uze ukhule kunaloku?”

Neli: “Ngabe wangimela ngakhula kancane”.

Researcher: Umcwaningi abutisise.... “Yini leyakwenta weva kanjalo?”

Neli: “Ngiva ngatsi nasengimdzala bengitotemukela kancono leti ndzaba leti”.

Researcher: “Waphindze wevani futsi lokunye?”

Neli: Aah.... “Ngacabanga kutsi shotsi sengihlukile kulabanye bantfwana ngaphindze ngatibuta kutsi sengitophila kanjani kusukela nyalo”.

Researcher: “Utiva unjani kutsi uphila neligciwane le HIV?”

Neli: “Ngitiva ngikhululekile ngoba wonkhe muntfu emndenini wami uyangikhutsata. Bayangikhumbuta kutsi nginatse emaphilisi ami nekutsi ngitimisele etifundweni tami”.

Researcher: “Emaphilisi akho uwanatsa ngabani sikhatsi? Ikhona yini inkinga lakunika yona?”

Neli: “Ngiwanatsa nga 7 ntsambama, ngakhetsa yena ngoba ngisuke sengisekhaya ngaleso sikhatsi. Emaphilisi akangihluphi ndzawo”.

Researcher: “Uyasati yini simo sengati salaba lotalwa nabo?”

Neli: “Yebo bete ligciwane”.

Researcher: “Kukhona yini losewuke wabatjela ngesimo sakho sengati lokungaba tihlobo noma bangani?”

Neli: “Chake kute lengike ngamtjela”.

Researcher: “Bangani bona ke sewakhona yini kubatjela?”

Neli: “Chake”.

Researcher: Umcwaningi abukisise umcwaningwa.... “Yini leyenta ungakhoni kubatjela ngesimo sakho sengati?”

Neli: Adlale ngetandla... “Ngicabanga kutsi batobese bangi phatsa ngendlela lehlukile kulabanye ngoba ngine HIV bacale kukhuluma tintfo letingasiko kahle”.

Researcher: Umcwaningi abutisise.... “Ngicela ungichazele kabanti kutsi usho kutsini nawutsi tintfo letingasiko kahle?”

Neli: “Batotjela labanye lendzaba bese iyandza kanjalo igcine seyingibangela emehlo ebantfu”.

Researcher: “Awubatsembi ngisho bangani bakho kutsi bangayigcina etifubeni tabo lendzaba?”

Neli: “Chake angibatsembi bangani bami, sikhuluma ngako konkhe phandle kwe HIV”.

Researcher: “Ucabanga kutsi ungakhona yini kubatjela emalangenini letako noma ukholelwa kutsi indzaba yakho lena?”

Neli: “Chake, ngikholelwa kutsi yindzaba yami, ngingabachazela njani nje kutsi ngayitfoli njani? Noma ngingatsini, batongihleba batsi ngititfole ngekulala ngiko nginayo”.

Researcher: “Utisita njani kutsi uhlale ungakakhatsateki emoyeni wakho naloku uphila neligciwane le HIV?”

Neli: “Kute lokungikhatsatako ngoba ngitsatsa ngekutsi angikehluki kulabanye bantfwana, sengite lemicabango yekutsi ngihlukile ngoba bayasifundzisa ku teen club nge HIV nekutsi ungaphila njani nayo. Nyalo sengiyati kutsi ngiyafana nalo ne hayihayi nome shukela”.

Researcher: “Kube bekuya ngawe bowungafisa kutsi ngabe watiswa kanjani ngesimo sakho sengati?”

Neli: “Ngifisa ngatsi ngabe ngatjelwa emtfolamphilo”.

Researcher: Umcwaningi abutisise umcwanigwa.... “Yini lekwenta unconote umtfolamphilo?”

Neli: “Bekutoba melula kimi ku sheshe ngive ngoba bachaza kuvakale emtfolamphilo”.

Researcher: “Umtali wakho wakutjela njani ngesimo sakho sengati, kanye noma emahlandla lahlukene?”

Neli: “Wangitjela kanye, leletinye tikhatsi besuke kukhona lengikubutile”.

Researcher: “Unayo yini imibuto longafisa kuyibuta kimi?”

Neli: “Chake ngite”.

Researcher: “Ngiyabonga sikhatsi sakho”.

Neli: “Kulungile usale kahle”.

Interview 2 with Joseph English version

Researcher: The researcher passed greetings and welcomed the participant.... “Good morning, please tell me briefly about yourself (how old you are, which school you attend, your type of family)”.

Joseph: “I am 17 years old, I live at Nyonyane area. I last attended school in 2015 at Valley primary and I was in Grade 6. Currently I am not at school because when schools opened this year I got sick with TB and by the time I recovered time had gone so I decided will start next year”.

Researcher: “Why are you in lower grades when you are 16 years old?”

Joseph: Looking at the floor... pauses before he answers and displays being uncomfortable... “My mother enrolled at school in grade one when I was 10 years old”.

Researcher: “Please explain your type of family”.

Joseph: “I live with my biological mother and maternal grandparents and uncle. My father passed away when I was young and I don’t remember him too well. I am the first born followed by four girls aged 13, eight, five and two years”.

Researcher: “What is your experience of HIV status disclosure?”

Joseph: Eish.... “I was told when I was seven years old. At that time, I was young and didn’t understand much. I got to understand as I grew older and I was scared about my health. It was in 2013 and I was in Grade 3 when I started understanding. What came to my mind was how did I get this illness and my mother was scared to tell me, she only got to tell me recently. I felt like stopping taking the treatment. I also asked why I was the only one who was affected as I’m the only one from my siblings who is living with HIV.

Researcher: A moment of silence. “Can you tell me how you got to know your HIV status (when, where and who told you)?”

Joseph: “I was told by my mother when we were at home when I was doing Grade 3 after I asked her why I was the only one taking medication at home. She then explained to me why”.

Researcher: “How did you feel immediately after learning about your HIV status?”

Joseph: “I was angry and scared about what would happen to me, did this mean that my death was near?”

Researcher: The researcher probes by asking... “Who were you angry at?”

Joseph: Looking like he still had the anger in him... “I was angry at the situation, why me? But I did not blame my mother”.

Researcher: Pause ...moment of silence “As an individual how does living with HIV make you feel?”

Joseph: “Now I feel free because some of my friends that I used to go to school with are also on treatment. I see them at the support group. Even when I feel scared, being with them gives me courage, so most of the time I feel free now”.

Researcher: “Have you been able to confide in others about your status e.g friends or significant others?”

Joseph: “No I haven’t told anyone”.

Researcher: “If you have not disclosed, what is holding you back from disclosing your status?”

Joseph: Eish.... “No one knows, even my friends don’t know, I don’t trust people because you tell one person and then you will hear your story from other people. I even told my mother not to tell her friends about my status because I also didn’t choose to have HIV”.

Researcher: “Were you telling her because you had heard her telling others?”

Joseph: Looks at the researcher... “No I hadn’t heard her telling others but I was just requesting that she keeps it confidential because some people when they run out of stories they then say things that they are not supposed to say”.

Researcher: “What about your own friends, have you told them?”

Joseph: “You know with friends it is difficult because you can be friends today and have a small misunderstanding tomorrow. The friend will then tell others who will then talk about me. As for us guys we go here and there so you may hear people talking and point at you. No matter how much I trust him today I cannot tell him because tomorrow we may not be friends”.

Researcher: “How do you cope with your HIV status?”

Joseph: “I work at a local bar as a cleaner so it helps me, I also watch TV at the bar or at home. I also like listening to music on my phone. I used to dance when at school because I was with my peers”.

Researcher: “Your working at a bar, doesn’t it influence you to drink alcohol as well?”

Joseph: “No it doesn’t because I understand that drinking alcohol will affect my life and I may then get sick”.

Researcher: “If things were to be done differently how do you think your HIV status should have been disclosed to you?”

Joseph: Pause... “I liked the fact that I was told by mother because she answered my questions well when I asked for clarification”.

Researcher: “Did your mother disclose all the information about HIV at once or in stages?”

Joseph: “She told me at once, when I wanted to know something she would explain to me on different occasions”.

Researcher: “Do you have problems with your ART?”

Joseph: “No I don’t have problems at all, I know that it keeps me healthy”.

Researcher: “Do you have questions for me about anything?”

Joseph: “No I don’t have any questions, all is clear at the moment”.

Researcher: “Thank you for your time”.

Joseph: “Welcome”.

Interview 2 with Joseph Siswati version

Researcher: Umcwaningi wacala ngekuvusela umncwaningwa wase uyamemukela “Sawubona, njengoba besengitetfulile mine ngicela ungitjele kafishane ngawe (kutsi unamingaki iminyaka, ufundzaphi nekutsi usuka ekhaya lelinjani)”.

Joseph: “Iminyaka yami ilishumi nesikhombisa, ngihlala e Nyonyane. Ngagcina esikolweni ngemnyaka wa 2015 e Valley primary bengifundza libanga lesitfupha. Nyalo angifundzi ngoba nakuvulwa tikolwa kulomnyaka ngagula ngaphatfwa yi TB. Ngesikhatsi ngiba ncono sikhatsi besesihambile ngase ngibona kutsi ngitobuyela emnyakeni lotako”.

Researcher: “Yini leyenta ufundze libanga leliphansi kantsi sewuna 16 weminyaka?”

Joseph: Abuke phansi..... athule atjengise kungakhululeki... “Make wangimikisa kuyocala esikolweni nangineminyaka lelishumi”.

Researcher: “Ngicela ungichazele ngemndeni wakho”.

Joseph: “Ngihlala namake longitalako nagogo namkhulu labatala make namalume. Babe washona ngisemncane angimkhumbuli kahle. Mine ngiwekucala kute emantfombatane lamane laneminyaka lalishumi nesitsatfu, siphohlongo, sihlanu nalemibili”.

Researcher: “Ngifisa kuva imicabango nendlela lowativa ngayo mzu kwana watiswa ngesimo sakho sengati mayelana neligciwane le HIV njengemuntfu lomusha?”

Joseph: Eish.... “Ngatjelwa ngesimo sami nangineminyaka lesikhombisa. Ngaleso sikhatsi bengisemuncane ngako angizange ngicondzisise kahle. Ngakhona kucondza nangikhula kwaba ngulapho khona ngicala kwesabela imphilo yami. Umnyaka bekungu 2013 ngifundza libanga lesitsatfu nangicala kucondza. Lokwafika engcondvweni yami

kwaba kutsi ngikutfolephi lokugula, namake bekesaba kungitjela uze wangitjela muva. Nakangitjela ngeva ngatsi ngabe ngiyekela lamaphilisi. Ngaphindze ngatibuta kwekutsi leni mine ngedvwa ngoba ngimi kuphela kulaba bakitsi lophila neligciwane le HIV.

Researcher: Kuthule sikhashana.... “Ungangitjela yini kutsi wati kanjani ngesimo sakho sengati (nini, bewukuphi indzawo nekutsi watjelwa ngubani)?”

Joseph: “Ngatjelwa ngumake sisekhaya, bengifundza libanga lesitsatfu emuva kwekuba ngimbute kutsi kwentiwa yini kutsi kube ngimi kuphela lonatsa emaphilisi ekhaya. Wase uyangichazela kutsi kwentiwa yini”.

Researcher: “Wativa unjani emuva kwekuba utjelwe ngesimo sakho sengati?”

Joseph: “Ngakwata ngaphindze ngetfuka kutsi kutawukwentekani kimi, ngatibuta kutsi loku besekusho kutsi sengitoshona yini?”

Researcher: Umcwaningi abutisise.... “Bowukwatele bani?”

Joseph: Umcwaningwa abukeke ngatsi kubuya kukwata.... “Bengikwatele lesimo kutsi leni mine? Kepha bengingamsoli make”.

Researcher: Kuthule sikhashana “Utiva unjani kutsi uphila neligciwane le HIV?”

Joseph: “Nyalo ngitiva ngikhululekile ngoba labanye bangani bami lebengiya nabo esikolweni banatsa emaphilisi. Ngibabona la ku support group. Nome ngabe ngiyesaba, uma nginabo ngitiva ngiba nesibindzi, ngakoke cishe sonkhe sikhatsi sengitiva ngikhululekile”.

Researcher: “Kukhona yini losewuke wabatjela ngesimo sakho sengati lokungaba tihlobo noma bangani?”

Joseph: “Chake kute lengike ngamtjela”.

Researcher: “Nangabe kute loke wantjela yini leyenta ungakhoni kubatjela labanye ngesimo sakho sengati?”

Joseph: “Eish Kute lowatiko, ngisho bangani bami abati, angibetsembi bantfu ngoba utjela umuntfu munye bese uva indzaba yakho seyikulabanye bantfu. Ngamtjela ngisho namake kutsi angabatjeli bangani bakhe ngesimo sami sengati ngoba nami angizange ngikhetsa kuba neligciwane le HIV”.

Researcher: “Bewusho ngoba bowumuve atjela labanye yini?”

Joseph: Abukisise umcwaningi... “Chake bengingakamuva atjela labanye kepha bengimcela nje kutsi ayigcine esifubeni sakhe ngoba labanye bantfu naseba phelelwe tindzaba babese bakhuluma tintfo labangakafaneli kutikhuluma”.

Researcher: “Bangani bakho ke, bona sewubatjelile yini?”

Joseph: “Yati bangani leyabo ilukhuni ngoba ningaba bangani namuhla bese niyahishana kusasa. Loyo mngani utobese utjela labanye ngami. Tsine emajita sihamba

lapha nalapha ngako ke ungeva bantfu bakhuluma sebakukhomba. Ngakoke noma ngabe ngimtsemba kanganani umngani namuhla ngeke ngimtjele ngoba kusasa kungenteka singasabi bangani”.

Researcher: “Utisita njani kutsi uhlale ungakakhatsateki emoyeni wakho naloku uphila neligciwane le HIV?”

Joseph: “Ngisebenta e bar ngiya cleaner kuyangisita, ngiphindze ngibukele i TV khona lemsebentini noma ekhaya. Ngiphindze ngitsandze kulalela umculo elucingweni lwami. Nangisafundza bengivame kujayiva nebangani bami”.

Researcher: “Lokusebenta e bar akukufakeli yini silingo sekunatsa tjwala?”

Joseph: “Chake akungifakeli ngoba ngiyati kutsi kunatsa tjwala akungilungeli futsi kungangigulisa”.

Researcher: “Kube bekuya ngawe bowungafisa kutsi ngabe watiswa kanjani ngesimo sakho sengati?”

Joseph: Athule sikhashana... “Ngatsandza lokutsi ngitjelwe ngumake ngoba wangiphendvula kahle konkhe bengikubuta wangichazela ngeva”.

Researcher: “Umtali wakho wakutjela njani ngesimo sakho sengati, kanye noma emahlandla lahlukene?”

Joseph: “Wangitjela kanye, uma sengimubuta etikhatsini letilandzelako bekangichazela lelengikubutako”.

Researcher: “Tikhona yini tinkinga lonato ngemaphilisi?”

Joseph: “Chake kute tinkinga lenginato, ayangisita kutsi ngihlale ngiphilile”.

Researcher: “Ikhona yini imibuto lonayo longafisa kutsi ngiyiphendvule?”

Joseph: “Ngite, konkhe kuyacaca kwanyalo”.

Researcher: “Ngiyabonga sikhatsi sakho”

Joseph: “Wamukelekile”.